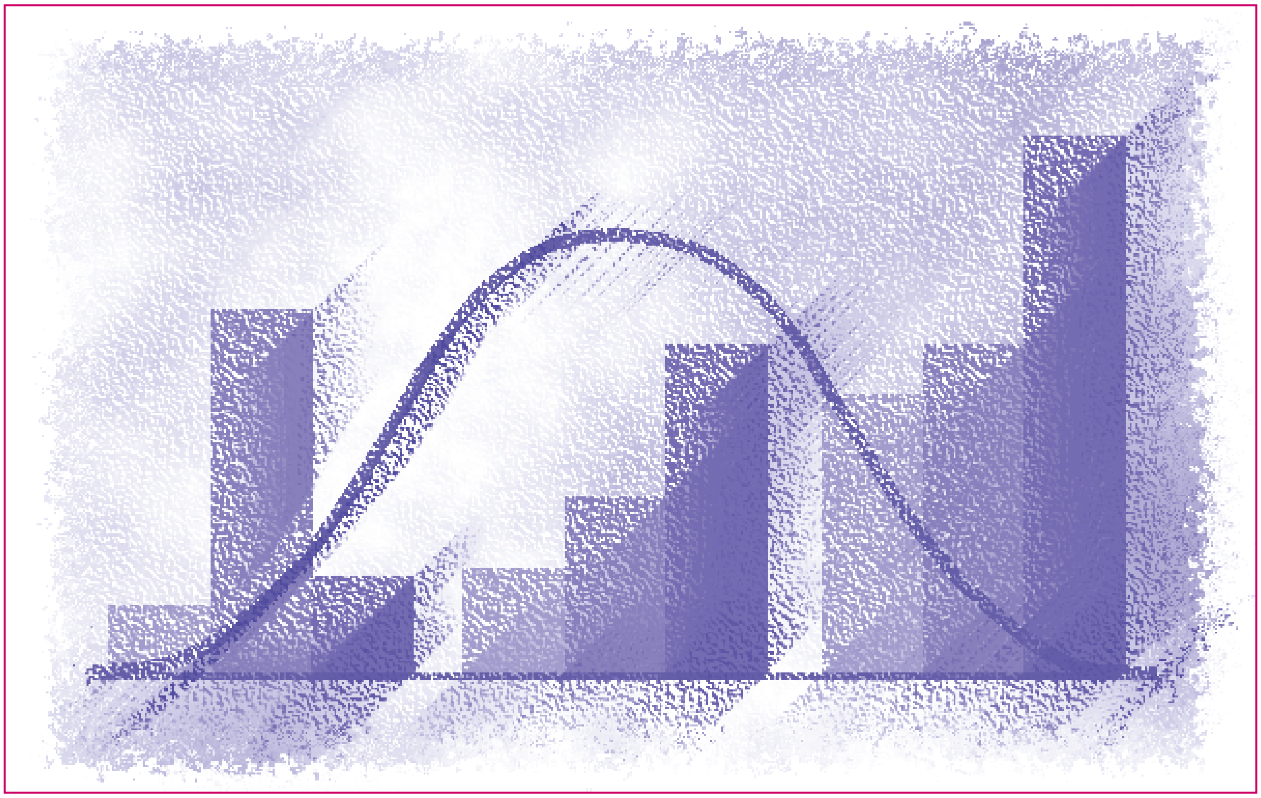


HEALTH SURVEY RESEARCH METHODS

CDC

CENTERS FOR DISEASE CONTROL AND PREVENTION

DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention
National Center for Health Statistics

Ninth Conference on

HEALTH SURVEY RESEARCH METHODS

Edited by
Lu Ann Aday and Marcie Cynamon

DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention
National Center for Health Statistics
Hyattsville, Maryland

May 2010

The findings and conclusions in this report are those of the authors and do not necessarily represent the views of the National Center for Health Statistics, Centers for Disease Control and Prevention.

CONTENTS

Disclaimer: *This report contains the papers and formal and floor discussions presented at the 9th Conference on Health Survey Research Methods. It does not reflect the views or opinions of the National Center for Health Statistics (NCHS) or the Centers for Disease Control and Prevention (CDC). The editors co-chaired the conference and the University of Illinois provided copy editing. NCHS as a supporter and organizer of the Conference has published these Proceedings as a courtesy.*

SESSION 1: EMERGENCY PREPAREDNESS AND SURVEILLANCE

SESSION 2: MEASUREMENT ERRORS AND HEALTH DISPARITIES

SESSION 3: CHALLENGES OF COLLECTING SURVEY-BASED BIOMARKER AND GENETIC DATA

SESSION 4: THE RELATIONSHIP BETWEEN SURVEY PARTICIPANTS AND SURVEY RESEARCHERS

SESSION 5: TRADE-OFFS IN HEALTH SURVEY DESIGN

ACKNOWLEDGMENTS

We gratefully acknowledge the generous support of a number of federal agencies and survey research organizations in funding the conference: Abt Associates, Inc.; Agency for Healthcare Research and Quality; Health Resources and Services Administration; Mathematica Policy Research, Inc.; Mayo Clinic College of Medicine; National Cancer Institute; National Center for Health Statistics; National Opinion Research Center, University of Chicago; Office of Behavioral and Social Sciences Research, NIH; Research Triangle Institute International; Substance Abuse and Mental Health Services Administration; University of Michigan; and Westat. The conference would not have been possible without the generous sponsorship of these organizations.

The conference was planned and implemented by a steering committee comprised of representatives from academic and research organizations and the federal agencies that provided support for the conference. The committee was very active and involved in obtaining funding for the conference, deciding upon the topics to be addressed, organizing and facilitating the conference sessions, and preparing the conference proceedings. Members of the steering committee included Timothy Beebe, Mayo Clinic College of Medicine; Stephen Blumberg, National Center for Health Statistics; Anne Ciemnecki, Mathematica Policy Research, Inc.; Steven Cohen, Agency for Healthcare Research and Quality; William Davis, National Cancer Institute; Brad Edwards, Westat; Trena Ezzati-Rice, Agency for Healthcare Research and Quality; Joseph Gfroerer, Substance Abuse and Mental Health Services Administration; Timothy Johnson, University of Illinois at Chicago; Alice Kroliczak, Health Resources and Services Administration; James Lepkowski, University of Michigan; John Loft, RTI International; Robert Mills, Health Resources and Services Administration; Judie Mopsik, Abt Associates, Inc.; Deborah Olster, Office of Behavioral & Social Sciences Research, NIH; Colm O'Muircheartaigh, NORC, University of Chicago; and Dicy Painter, Substance Abuse and Mental Health Services Administration. Lu Ann Aday, University of Texas School of Public Health and Marcie Cynamon, National Center for Health Statistics, served as co-chairs of the conference steering committee.

We also want to thank all of those who contributed papers to the conference, presented formal discussion papers, contributed to the floor discussion; and served as session rapporteurs. The fruit of your labors is documented in these proceedings.

We express our special gratitude to the conference staff affiliated with University of Illinois at Chicago who attended to all of the organizational details in making the conference a success: Diane O'Rourke, conference organizer, who ably handled the multitude of organizational logistics for the conference; Lisa Kelly-Wilson, conference staff, who assisted Diane with the arrangements for the conference and also did yeoman's work in editing the conference proceedings; and Kris Hertenstein, conference staff, who worked behind the scenes to support Diane, Lisa, and the conference steering committee.

We enjoyed the opportunity to contribute to this wonderful conference and hope that these proceedings will be a resource to all of those who seek to enhance the rigor and relevance of health surveys.

Lu Ann Aday
Marcie Cynamon

EXECUTIVE SUMMARY

Lu Ann Aday, *University of Texas School of Public Health*

PREVIOUS CONFERENCES

The Conference on Health Survey Research Methods held at Peachtree City, Georgia, March 2–5, 2007, is the 9th in a series of conferences initiated in the 1970s to identify the methodological issues that need to be addressed in strengthening the design and conduct of health surveys. The dates and locations of the previous conferences are as follows:

1975	Airlie, Virginia
1977	Williamsburg, Virginia
1979	Reston, Virginia
1982	Washington, DC
1989	Keystone, Colorado
1995	Breckenridge, Colorado
1999	Williamsburg, Virginia
2004	Peachtree City, Georgia

The first (1975) conference was comprised of over 50 survey researchers who gathered informally to discuss critical areas of research in health survey methods; what was known and what still needed to be the focus of research in this area; as well as related recommendations for research funding, policy, and guidance for the design and conduct of health surveys based on the body of available evidence. No formal papers were solicited or submitted at this conference, but conference discussions were summarized and published in a conference proceedings report (National Center for Health Services Research [NCHSR], 1977).

The second and successive conferences provided periodic opportunities to address major health survey methods issues. In these later conferences, formal papers were solicited and invited; opportunities provided for individuals or panels to comment on the papers; and ample time allowed for floor discussion, which was summarized and incorporated into the conference proceedings. Eighty researchers attended the most recent conference. A listing of the proceedings published for each of the conferences appears at the end of this summary.

CONFERENCE GOALS

The goals of the first (1975) conference, which remained timely and appropriate in guiding the organization of the 9th conference as well, are listed below:

- “To identify the critical methodological issues or problem areas for health survey research and the state of the art or knowledge with respect to these problems.
- [To identify] what types of research problems need to be given high priority for research funding.
- To identify policy issues that can be addressed by survey research scientists.
- To communicate the results, recommendations, and implications of this conference to:
    - the broader community of health researchers who use survey methods;
    - relevant Government agencies and individuals; and
    - other potential users of [the] results of this conference” (NCHSR, 1977, p. iii).

A steering committee of researchers and representatives of government agencies and data collection firms and entities helped to identify topics and related sessions for the conference; send out general calls for papers as well as invited selected papers to be prepared and presented; and finalized the selection of papers, participants, and overall organization of the conference.

SESSIONS

The topics selected for the 9th conference are listed below. The proceedings that follow are organized accordingly in terms of the *Session Introduction*, *Feature Papers*, *Discussion Papers*, and *Discussion Summaries* for each of the respective sessions:

1. Emergency Preparedness and Surveillance
2. Measurement Error and Health Disparities
3. Challenges of Collecting Survey-Based Biomarker and Genetic Data
4. The Relationship between Survey Participants and Survey Researchers
5. Trade-offs in Health Survey Design

The conference steering committee attempted to select a mix of topics that addressed timely and emerging issues (e.g., emergency preparedness and surveillance, measurement error and health disparities, challenges of collecting survey-based biomarker and genetic data), as well as new and innovative approaches to enduring methodological problems (e.g., the relationship between survey participants and survey researchers, trade-offs in health survey design).

RESEARCH AGENDA

An important felt responsibility on the part of the steering committee was to clearly distill and define the health survey methodological research agenda to (1) highlight research priorities in an area and (2) provide an impetus for research funding to be directed to these areas. Table 1 summarizes the research priorities based on the respective conference sessions, organized according to the major dimensions in designing and conducting health surveys: study design, sample design, data collection, measurement, data preparation, and data analysis. The table is intended to consolidate a look at the program of health survey methods research that is needed to strengthen the design and conduct of health surveys both now and in the future.

CROSSCUTTING ISSUES

A number of crosscutting themes emerged across the respective conference sessions in terms of grounding a look at needed methodological research on health surveys:

- **Best practices.** A recommendation across the series of sessions is that the corpus of methodological research in a defined area of study should provide specific guidance regarding the "best practices" in the conduct of health survey research in that area. "Best practices" are methods that have been deemed to be both feasible and sound in the everyday conduct of survey research, based on both formal methodological research and practical research experience.
- **Adaptive and responsive designs.** Another important assumption underlying a number of the sessions is that the designs underlying the conduct of health survey research may need to be fluid rather than fixed. Conventional health survey design typically has assumed that a well-planned blueprint is needed to guide the conduct of the study. Adaptive and responsive survey designs acknowledge that well articulated benchmarks for evaluating the survey as it proceeds also may be helpful for enhancing the overall quality of the study.
- **Conventional vs. innovative procedures.** A key design choice in the conduct of health surveys relates to the "pull and tug" of employing innovative but relatively untried survey procedures versus adapting or extending ongoing studies and data collection activities to address emergent public health or health care issues (e.g., emergency preparedness and surveillance). To best address such issues, the truth may well lie in doing both.
- **Cross-disciplinary methods.** The conduct of high-quality survey research requires a variety of disciplines, methods, and expertise. For example, clinical medicine and practice can guide the selection of key biomeasures in the conduct of health surveys, but the fund of know-how from the field of health survey research can assure that these measures are collected in a valid and reliable fashion.
- **Trade-offs in timeliness vs. quality.** Policy makers often demand timely answers to questions and the ready availability of evidence to guide resource allocation decisions. A ponderous attention to assuring the quality of surveys may be costly in terms of the *de facto* relevance of the information gathered. On the other hand, an urgency to provide expeditious answers may compromise the quality of the data that is made available. Survey researchers

must be attuned to innovative techniques and technologies for minimizing and balancing these respective "costs."

- **Ethics of risks vs. benefits to respondents, interviewers, and the consent process.** Surveys essentially may entail either rewarding ***or*** costly transactions between study respondents and survey data collectors. Ethical norms for evaluating these transactions relate to (1) whether there is full, informed, and autonomous consent on the part of study participants to engage in the process; and (2) what are the benefits relative to risks for both the study respondents *and* those charged with inviting them to participate.

Table 1. Health Survey Methods Research Agenda Based on Conference Sessions

SURVEY DESIGN	**Emergency Preparedness & Surveillance (*Session 1*)**	**Measurement Error & Health Disparities (*Session 2*)**	**Challenges of Collecting Survey-Based Biomarker & Genetic Data (*Session 3*)**	**The Relationship between Survey Participants & Survey Researchers (*Session 4*)**	**Trade-offs in Health Survey Design (*Session 5*)**
Study design	• Feasibility of the use of ongoing or rapid response registries & alternative longitudinal designs for long-term surveillance of the health effects of disasters on affected populations	• Evaluation of how the context for survey questions & survey administration may differentially affect responses to sensitive questions for different groups	• Evaluation of the timing, tiering, & level of disclosure during the consent process for obtaining biomeasures & related feedback of results to respondents • Embedding of methodological experiments in large-scale studies to enhance the quality of biomeasures	• Triangulation of different designs for evaluating how trust/ mistrust influences survey response rates (e.g., community-based participatory research [CBPR], laboratory experiments, cultural analyses, historical trends, & business solutions analysis)	• Reconceptualization of survey design as fluid rather than fixed • Elements of a system of forecasting tools for evaluating the trade-offs in error & costs in *responsive designs* for the continuous monitoring of survey quality
Sample design	• Innovative, unbiased, timely, & collaborative methods for case identification, construction of representative multiple-frame samples, & adaptive linked designs for sampling diverse populations affected by emergencies	• Methods for reducing the undercoverage & nonresponse of at-risk populations to minimize errors in health survey estimates for these groups	• Complexities in designing & drawing survey samples for which biomarker data will be collected	• Evaluation of the trade-offs in the representativeness vs. the relationship-building nature of CBPR samples in terms of addressing study objectives	• Evaluation of the trade-offs in complex sample designs for total, subgroup, & over-time estimates
	• Timeliness & relevance of other existing or ongoing data collection systems (e.g., U.S. Census, BRFSS, public health department surveillance systems, USPS delivery	• Generalizability of the estimates of validity & reliability of health survey self-reports across modes of survey administration • Evaluation of the fit of interviewers	• Evaluation of the strengths & weaknesses of alternative biomeasure data collection platforms, e.g., mode and location (household- *vs.* clinic-based) • Methods &	• Analysis of the impact of individual- vs. structural-level impediments to survey participation • Effects of shifting the perspective of survey respondents to understanding their roles as	• Evaluation of the cost & error qualities of alternative & mixed-mode data collection strategies

Data collection	counts) for monitoring the impacts of emergencies • Strengths & weaknesses of multimode disease reporting systems & surveys for monitoring the impacts of emergencies	with survey subject matter & study population	criteria for the selection & training of interviewers for collecting biomeasures • Evaluation of methods for enhancing response rates in collecting biomeasures	*consumer* or *community resident* on survey participation • Role of incentives in survey participation	
Measurement	• Valid & reliable approaches to cognitive testing, usability testing, & pretesting of rapid response survey questionnaires as well as pre-event disaster-specific question modules • Development & validation of disaster classification schemes	• Application of multiple-indicator multiple-cause (MIMIC) models & related differential item functioning (DIF) to assess the equivalence of health-related measures across diverse population subgroups • Evaluation of the impact of readability assessments of survey questionnaires on the stability & accuracy of responses for low-literacy populations	• Criteria for the selection & validity & reliability analysis of biomeasures & equipment	• Evaluations of the cultural sensitivity of survey instruments in relationship to the validity & reliability of survey measures • Evaluations of respondent-centered survey design on data quality	• Criteria for the selection of *leading indicators* of responsiveness to survey quality
Data preparation	• Parameters for the design of contingency plans for data systems & access during an emergency	• How to deal with differential response rates for criterion measures & the match of the recall period for survey questions & the time-of-use sensitivity of the criterion measures (e.g., hair & urine samples) in validating survey self-reports	• Methods for assuring the quality control of collected specimens	• Criteria for determining the "fitness of use" of survey measures	• Development & implementation of *Computer-Assisted Survey Information Collection (CASIC)* systems for monitoring errors in the survey process • Alternative approaches (e.g., simulation, sensitivity analysis) for estimating & adjusting for likely nonresponse bias
Data analysis	• Approaches to the unbiased weighting & construction of estimates for data collected from multiple sample frames	• The *reliability* of measures of reliability as a function of prevalence (e.g., kappa statistic) • The *validity* of validity correction factors to adjust for over/ underreporting	• Analysis of biomeasures as complements vs. substitutes for survey self-reports	• Analysis of the relative importance of risk of disclosure, perceptions of risk, & privacy & confidentiality concerns on survey participation	• Application of statistical models for estimating error trade-offs based on *para* (available process) data

PREVIOUS CONFERENCE PROCEEDINGS (by year of publication)

National Center for Health Services Research. (1977). *Advances in health survey methods: Proceedings of a national invitational conference*. (DHEW Publication No. [HRA] 77-3154). Rockville, MD: Author.

National Center for Health Services Research. (1978). *Health survey research methods: Second biennial conference*. (DHEW Publication No. [PHS] 79-3207). Hyattsville, MD: Author.

Sudman, S. (Ed.). (1981). *Health survey research methods: Third biennial conference.* (DHHS Publication No. [PHS] 81-3268). Hyattsville, MD: National Center for Health Services Research.

Cannell, C. F., & Groves, R. M. (Eds.). (1984). *Health survey research methods: Proceedings of the Fourth Conference on Health Survey Research Methods.* (DHHS Publication No. [PHS] 84-3346). Rockville, MD: National Center for Health Services Research.

Fowler, F. J. (Ed.). (1989). *Health survey research methods: Conference proceedings*. (DHHS Publication No. [PHS] 89-3447). Rockville, MD: National Center for Health Services Research.

Warnecke, R. B. (Ed.). (1996). *Health survey research methods: Conference proceedings.* (DHHS Publication No. [PHS] 96-1013). Hyattsville, MD: National Center for Health Statistics.

Cynamon, M. L., & Kulka, R. A. (Eds.). (2001). *Seventh conference on health survey research methods.* (DHHS Publication No. [PHS] 01-1013). Hyattsville, MD: National Center for Health Statistics.

Cohen, S. B., & Lepkowski, J. M. (Eds.). (2004). *Eighth conference on health survey research methods*. (DHHS Publication No. [PHS] 04-1013). Hyattsville, MD: National Center for Health Statistics.

INTRODUCTION TO SESSION 1: Emergency Preparedness and Surveillance

Trena M. Ezzati-Rice, *Agency for Healthcare Research and Quality*

National and international events—such as the September 11, 2001, terrorist attacks; Severe Acute Respiratory Syndrome (SARS) outbreak; sequential hurricanes in Florida (2004) and the Gulf Coast region (2005); and the recent influenza vaccine shortage—and the potential for future events—such as global spread of pandemic influenza—clearly have raised awareness of the need for enhanced systems and methods for collecting health and other related data to monitor a population's health. Thus, there is perhaps no more current and challenging survey methods research issue than developing and implementing methods to facilitate public health surveillance following disasters, disease outbreaks, or a bioterrorism event.

In this session, new methodologies and adaptations of existing ones are discussed for the collection and dissemination of time-sensitive data in response to potential bioterrorism and natural disasters. The presenters in this session share the common goal of not only conducting research on emergency preparedness and surveillance but also implementing methods to address current and emerging issues. Clearly, the papers in this session have a great deal to offer to health survey methods research and can help guide the development of a set of "best practices." They were specifically chosen to set the stage for a stimulating discussion regarding the methodological challenges, both current and future, of bioterrorism and surveillance-based research. Lessons learned based on recent and ongoing research to prepare for future emergencies are a major focus of the papers in this session.

The paper by Allison Plyer and colleagues contains practical examples from a local perspective of data coordination and dissemination in a post-disaster area. They discuss real-time data dissemination in New Orleans before and after Hurricane Katrina on a Web site that had been in place before the hurricane. The data made available on the site were drawn from different sources, including information on the extent of the flooding and local information, such as monthly school enrollment counts. Currently, the Web site is used primarily to monitor the recovery from the hurricane. Throughout the paper, a common theme is the need for data, data, and more data (especially at the local level)—but most importantly, the need for *timely* data necessary to make key decisions. This paper contains important lessons on preparedness, provides some practical guides on how to prepare for a disaster, and speaks to Plyer's "Ask Allison" celebrity status.

The paper by Paul Pulliam and coauthors addresses the challenges and specific methods used to develop a registry after the 2001 World Trade Center (WTC) disaster. This registry was set up to monitor the long-term health effects of environmental exposures for those who were in close proximity to the WTC when it collapsed or worked there afterwards during the recovery process. The authors also discuss a separate innovative Rapid Response Registry (RRR) that uses a brief questionnaire to collect contact information from persons who have survived a disaster. The RRR's goal is to establish a surveillance system within eight hours following a localized acute emergency. The methods employed and lessons learned with building lists of persons for both the WTC and RRR registries are summarized in the paper.

A unique monitoring system is discussed in the paper by Judie Mopsik and coauthors. This electronic data capture system was developed to monitor smallpox vaccine uptake and administration regarding a 2003 initiative targeting selected U.S. Army personnel (officers, enlisted service members, and some civilian defense personnel). The adaptation of traditional survey data collection methods, reporting compliance, and the evaluation of validity and reliability of the rapid response surveillance system are important aspects of this study.

The opportunities (as well as challenges) of using an ongoing health surveillance system for real-time data collection and monitoring of a possible or emergent public health crisis are discussed in the paper by Michael Link and coauthors. Two illustrative case studies detail how the Behavioral Risk Factor Surveillance System (BRFSS), a monthly state-based telephone survey, was used to provide critical timely information during two recent public health emergencies. The authors describe the strengths of using an existing system to rapidly obtain public health information when officials clearly know what data are needed.

In their paper, Ronald Kessler and collaborators address the difficult topic of what is an appropriate sample design for post-disaster mental health needs assessment surveys in the U.S. The paper provides a comprehensive discussion of pros and cons of alternative designs for various situations. A primary topic was developing sampling frames and sample designs. For surveying Hurricane Katrina evacuees, the use of multiple list frames was emphasized; however, RDD samples also were successfully incorporated. The use of multiple list frames and RDD samples makes the determination of selection probabilities more complicated, but it can reduce the sample size by a substantial amount. The positive presentation of opportunities using existing survey infrastructures is an encouraging note. While the potential for bureaucratic roadblocks do exist, the authors cite at least one success in this area.

In summary, the papers in this session highlight similarities as well as differences in survey methods research and surveillance-based research. They illustrate the importance of pre-planning, developing critical baseline data, establishing effective mechanisms for rapid post-event surveillance, and making use of existing infrastructures. The excellent research presented in this session highlights many of the key methodological successes and challenges for disaster-related health survey methods research.

FEATURE PAPER: Real-Time Data Dissemination in a Rapidly Changing Environment

Allison D. Plyer, Denice Warren, and Joy Bonaguro, *Greater New Orleans Community Data Center*

INTRODUCTION

Before Hurricane Katrina, the Greater New Orleans Community Data Center (GNOCDC), a project of Greater New Orleans Nonprofit Knowledge Works, used local, state, and federal data to inform interactions between government, funders, researchers, nonprofits, and community-based organizations. Our theory was that if all stakeholders were using the same information, we could better tackle the city's many challenges. After Katrina, our audience expanded to include federal agencies, national researchers, and the media. We assisted their understanding of the data landscape in New Orleans and facilitated connections with local organizations. Presently, population estimates and other essential information are being generated and updated by various researchers and government agencies. We actively scan the environment to find and assess all post-Katrina estimates and projections, and publish them in a highly usable, Web-based format. This paper contains practical examples of data coordination and dissemination in post-Katrina New Orleans.

PRE-KATRINA

The Greater New Orleans Community Data Center is a nonprofit initiative launched in 2001 to support local nonprofit organizations in easily accessing data they need for grant writing, planning, and advocacy. We publish a highly usable, highly credible, and very responsive Web-based data dissemination system. Our Web site allowed nonprofit organizations to easily access neighborhood-level data about people and housing in easy-to-analyze tables and downloadable spreadsheets of all the data we published. The data on the Web site were meant to answer 80% of the data questions that these organizations had. For the other 20%, we built a feature called "Ask Allison," through which we typically responded to requests on the same day. Before Katrina, our Web site attracted 5,000 unique visits per month which, in data intermediary circles, is pretty phenomenal. (Our counterpart in Washington, DC, for example, attracted 1,000 unique visitors each month.)

KATRINA

Then the storm hit. As the city evacuated, all of our data immediately became obsolete. However, the Web site was so well indexed on the Web that visits to www.gnocdc.org skyrocketed.

Anticipating that the traffic to our Web site would continue to increase, we realized we needed to provide information relevant to the emergency on our site. The initial step was to post an elevation map of New Orleans. Since all of the other New Orleans-based Web sites went down, this map was the first information available on the Internet that would give a clue as to which areas of the city might flood. In addition, we quickly posted a thematic map of poverty in Orleans Parish so that the story could be better told about the differing neighborhoods in New Orleans. We also emphasized on our home page that we were still up and running.

Once the rest of the country realized the scope of the disasters, the “Ask Allison” questions came flooding in. We received questions from a wide range of entities: federal agencies wanting information to help them in their response work; media wanting to know about different New Orleans neighborhoods; evacuated citizens trying to figure out whether their homes had flooded; and individuals trying to get in touch with relatives and friends. We knew that if individuals were asking us these questions, they were desperately seeking answers on the Web.

Although we didn’t have answers to many of these questions, we knew how to find the information on the Web and make it easy to use and understand. We created a couple of Web pages that directed inquiries to the best information as it became available. We searched several times a day for new sources of information and updated these Web pages frequently.

How Did We Do This & Evacuate at the Same Time?

Before the storm, we had one remote staff person. Our GIS specialist had moved to San Diego one month before the storm, and she was working part-time to finish up a mapping project for us. We were fortunate that our server was located in Kentucky. We had at one time used a local vendor but had not received the service we needed from that vendor and reluctantly moved our business to a company in Kentucky several years before.

On the Friday before the storm, the weather forecast indicated that the storm was not going to hit New Orleans, but just in case, we backed up all key files at the office. By Saturday, it appeared much more likely that the storm was coming directly towards New Orleans. We boarded up our homes and evacuated to either hotels or homes of friends out of town. We still managed to put up the elevation map on our Web site. The storm hit on Monday, and by Tuesday, the levees had failed and most of the city was flooded. At that point, we did not know when we would be able to go home, but we knew it would not be any time soon.

With only limited access to the Internet in friends’ homes and hotels, we made a plan to move to more permanent locations. While some of our staff started heading toward family in Phoenix and California, Plyer agreed to stay with friends in Georgia and continue to answer "Ask Allison" requests. When our first staff members were settled out west, she started heading to family in Chicago.

What Worked & What Didn't?

It was fortuitous that our server was in Kentucky and we had a staff person working remotely so that at least one person could "hold down the fort." We had very strong organizational procedures that allowed us to work efficiently with minimal communication. What we lacked were contingency plans. It was a matter of circumstance that our server and one staff person were remote from New Orleans. Since we had no access to our bank in New Orleans, our Executive Director had to devote herself to handling the administrative tasks of getting us our paychecks and getting our health insurance paid. This added responsibility made her unavailable for supporting our emergency content development and production.

POST-KATRINA

Gradually, most of the staff made their way back to New Orleans. Since the storm, our Web site now receives three times as many unique visits monthly as before the storm. The "Ask Allison" requests, which had hovered around 20 a month before the storm, reached 50 the month of the storm. When both the city and the nation started coming out of shock in January, people were looking for data to determine the scope of services New Orleans needed. Hence, the data requests grew dramatically. Much of the data that organizations had become accustomed to using no longer existed. The data on our Web site were not current, and the only option left to visitors was to "Ask Allison."

From our normal audience, we received predictable questions, albeit largely unanswerable. But our audience also was expanding significantly. "Ask Allison" acted like a Venus flytrap. As estimators and researchers began their work, they usually started by scanning the Internet, finding the GNOCDC site, and submitting a request for information we might be able to provide to support their work. Federal agencies, national researchers, commercial demographic estimators, the media, and national nonprofit organizations all contacted us for data. As a result, the GNOCDC was well positioned to facilitate connections among organizations and identify population and other estimates as they emerged.

Population Estimates

The question on everyone's mind was "Where did all the evacuees end up?" It became clear relatively quickly that FEMA would be the best data source on displaced New Orleanians. We believe the $2,000 benefit provided by FEMA to all residents of the New Orleans area who evacuated their homes would be a strong incentive for registering with FEMA.

However, FEMA was reluctant to release their data due to privacy concerns. In December 2005, FEMA finally released a data table of the locations of Katrina/Rita applicants by Metropolitan Statistical Area (MSA) of destination. FEMA then agreed to release the raw data to colleagues at the Census Bureau who could aggregate the data by smaller geographic areas. However, this data transfer wasn't completed until a year later.

By January 2006, the utility of the individual FEMA applicant data had diminished greatly. Households splintered, changes of address often were recorded as new applications, and the FEMA representatives taking calls stopped consistently asking for updated location information.

Continuous High-Ground Benchmark

By October 2005, service providers of all types needed to know how many people had returned to New Orleans. We decided to make an estimate of this although we knew this was outside our scope: we had no expertise for creating population estimates. We identified the census-block groups that had not been crossed by the flood line and added up the Census 2000 data for population and households in those block groups. We produced a map entitled "Pre-Katrina Population in Non-flooded Areas," noting that it was a "ballpark" figure of the number of people who may have been able to move back into their homes more quickly. This basic methodology turned out to be one on which many estimators and projectors, including the Rand Corporation (McCarthy, Peterson, Sastry, & Pollard, 2006), the Louisiana Department of Health and Hospitals (Chapman & Dailey, 2005), Claritas (Hodges, 2006), and ESRI (Wombold, 2006), heavily relied.

City of New Orleans, Emergency Operations Center

In October and November 2005, the City's Emergency Operations Center (EOC), with technical assistance from the CDC, piloted a rapid survey of the returned population in Orleans Parish. The purpose was to provide population information to facilitate the relief and planning efforts of city, state, federal, and nonprofit organizations with a particular emphasis on health service agencies.

The survey was implemented over two consecutive days. If the sample housing unit was unoccupied on the first visit (Saturday), surveyors left a door hanger packet. Each unoccupied residence was revisited two times, with no fewer than three hours between each visit. All third visits were completed on the second day of the survey (Sunday). If no response was recorded after the third visit, the house was considered to be unoccupied during the survey period. Additional rapid population estimate surveys were conducted in December 2005 and January 2006.

However, the EOC was reluctant to publish the data because of concerns that a widespread revelation about the relatively small number of New Orleanians who had returned would lead to a decrease in federal funding. In fact, they were told that distribution of the report had to be approved by the local Director of Homeland Security. They never published their findings from October and November 2005 and allowed for only limited distribution of their December 2005 findings. They finally released their January 2006 report in March 2006.

But the population was changing constantly as more and more people came back, moved in with relatives, found apartments, or started working on rebuilding their homes. Some method for frequent updates to population estimates was badly needed.

Louisiana Department of Health & Hospitals

In mid-December 2005, the Louisiana Department of Health and Hospitals began exploring methods to estimate the population in each parish to inform health-planning efforts. They were seeing population shifts out of northern parishes and back toward hurricane-affected parishes. These shifts were continual each month, so they needed monthly population estimates. Their estimates were based on a trended ratio of public school enrollment to the total population, as follows:

- Calculated the ratio of public school enrollment to general population estimates for each parish for 2000 through 2004.
- Established a five-year trend of enrollment/population ratio for each parish.
- Applied the resulting trend ratio to the monthly 2005 tally of public school enrollees to estimate parish population.

The problem with this approach was that so few public schools were open in Orleans Parish in January 2006 that estimates based on public school enrollment clearly were too low when compared with the results of the December *Rapid Population Estimate Survey*. This method, therefore, could not account for the estimated Orleans Parish population.

Census

Using the American Community Survey data, the Census Bureau produced special estimates of the New Orleans area for the first eight months of 2005 and the last four months of 2005. They released these estimates in the summer of 2006. These estimates give a sense of the population characteristics right after the storm in the last few months of 2005, but with so many changes in the city, by the time these data were released, they were no longer useful for informing decision-making.

The Census produces one total population estimate for each county (parish) each year and releases that estimate nine months after the date that the estimate represents. In a rapidly changing situation such as ours, an estimate of the total population in Orleans Parish from July 2006 released in March 2007 is not useful for making policy decisions in 2007.

To produce demographic estimates (income, age, occupation, etc.), the Census uses the American Community Survey, which is administered to a small sample of households one month, another small sample of households the following month, another small sample of households the following month, and so on. All of the data collected in a parish over the course of a year are averaged together to produce demographic estimates for each parish.

In July 2006, the Census released demographic estimates for Orleans Parish that averaged together survey data collected in the months of January through August 2005 with survey data collected in the months of September through December 2005. This kind of pre- and post-Katrina averaging produced 2005 demographic estimates for Orleans Parish that were very difficult to interpret.

Given the rapid change in Orleans Parish from January to December 2006, demographic estimates produced by averaging across all months in 2006 (and released in July 2007) also will not be helpful for decision making in 2007.

Professional Demographic Estimators

Commercial demographic estimators use methods that are similarly slow. The basis for their estimates is Census 2000 data. Then they use USPS residential counts and various consumer databases to identify where there have been significant changes in the number of households. They next apply a rate of change to the base Census 2000 demographic estimates each year to produce their own estimates. However, their processes entail significant massaging of the data, multiple checks and double-checks, geographic cuts, and production in various electronic media. Therefore, although USPS residential counts are available monthly, the inputs that commercial demographers use result in outputs produced many months later. For example, ESRI gathered USPS data in January/February 2006 from which they produced estimates that they didn't release until December 2006.

USPS Postal Counts

The GNOCDC is investigating the use of monthly USPS active residential postal delivery counts as a real time, sustainable, and readily available measure of changing population density.

Resource Information

Last spring, there were very few schools open in Orleans Parish. The State planned to open a large number of schools in the fall of 2006 in order to accommodate the largest possible number of returning students. However, as work on the damaged buildings progressed (or failed to progress), planned openings had to be cancelled. Nearly every day, changes were announced regarding the schools to be re-opened. These changes were so rapid that we started updating the maps every week and publishing them with a "best used by" date stamp to ensure that users always were aware of more current information. Now that the school situation has stabilized somewhat, we are publishing the maps monthly.

Immediately after the storm, the Emergency Operations Center (EOC) of the City was gathering information about which hospitals were open (via regular convenings of hospital managers), documenting the information, and circulating the document via e-mail. But the number of hospitals functioning, including their hours and services, continues to change as hospitals repair facilities and gain staff. The EOC method of gathering information about them did not ensure accuracy nor consistency of information, nor certainty of dissemination. Several months ago, we began working with the local 211 (information and referral) provider[Note] to gather hospital information frequently and consistently and publish it in monthly maps.

Similarly, we are working with the local 211 provider and the Louisiana Public Health Institute, which is regularly convening safety net clinics to document information about each clinic and its clients. We are publishing the data in monthly maps with directory information that they update frequently and regularly in a consistent format.

Recovery Indicators

The GNOCDC is now partnering with the Brookings Institution to monitor the recovery of New Orleans. Since December 2005, Brookings has tracked 40 indicators of New Orleans recovery and published them in *The Katrina Index* to provide members of the media, key decision makers, nonprofit and private sector groups, and researchers with an independent, fact-based, one-stop resource to monitor and evaluate the progress of on-the-ground recovery.

The GNOCDC will infuse local knowledge into *The Katrina Index* as well as new data sets to help local decision makers and nonprofit organizations better assess the progress and nature of the recovery. And some of the information will be mapped to visually demonstrate the extent to which different parts of the city are benefiting from various aspects of recovery.

Continued Data Dissemination

Behind the scenes, we continue to compile information about disparate surveying and research efforts taking place post-Katrina, to be able to cross-pollinate data sources and research initiatives via "Ask Allison."

CONCLUSIONS

Critical infrastructure data systems should have contingency plans that include off-site Internet service providers, as well as procedures and systems that allow personnel to continue their work even under evacuation conditions. These supports might include off-site staff or a pre-established evacuation location where lodging and loaned office space has been pre-arranged. In a post-catastrophe situation, standard sources are not set up to produce real-time estimates for the ensuing rapidly changing environment. The U.S. Census Bureau and even professional demographers are not equipped to produce accurate and timely data to meet post-disaster communities' needs. Their methods focus on accuracy and necessitate long lead times. Governmental agencies—at the city, state, *and* federal levels—should develop contingency plans for producing real-time rapid population estimates and for gathering and disseminating essential resource information under post-catastrophe conditions.

We were fortunate that in 2006 we had a calm hurricane season. We cannot control natural disasters. Will we be prepared for 2007 and beyond?

REFERENCES

Chapman, J., & Dailey, M. (2005). *Post-disaster population estimates*. Louisiana Department of Health and Hospitals DHH Bureau of Primary Care and Rural Health. Retrieved February 5, 2007, from www.gnocdc.org/reports/LA_DHHpop_estimates.xls

Hodges, K. (2006, May). *Claritas hurricane impact estimates: The Claritas challenge, The Claritas response*. Claritas Conference, California.

McCarthy, K. F., Peterson, D. J., Sastry, N., & Pollard, M. (2006). *The repopulation of New Orleans after Hurricane Katrina*. Rand Corporation. Retrieved February 5, 2007, from www.rand.org/pubs/technical_reports/2006/RAND_TR369.pdf

Wombold, L. (2006). *ESRI Gulf Coast updates methodology: 2006/2011*. Redlands, CA: ESRI. Retrieved February 5, 2007, from www.esri.com/library/whitepapers/pdfs/gulf-coast-methodology.pdf

[Note] 211 is a nationwide initiative of the United Ways of America and the Alliance for Information and Referral Systems. 211 providers gather and store information about human services and provide callers to the phone number 2-1-1 with information about and referrals to these human services for everyday needs and in times of crisis.

FEATURE PAPER: Methods to Improve Public Health Responses to Disasters

Paul Pulliam, Melissa Dolan, and Elizabeth Dean, *RTI International*

The ongoing effects of recent disasters have demonstrated a pressing need for accurate public health surveillance in the aftermath of events like Hurricane Katrina and the World Trade Center (WTC) disaster. The unpredictable timing and disruptive nature of disasters creates a number of challenges to public health surveillance. Surveillance programs following disasters need to be implemented quickly to gauge the immediate impact of the disaster; at the same time, they must be designed to follow individuals across time to measure long-term effects. Surveillance methodology should be flexible enough to allow the capture of public health information in a variety of environments and situations from diverse individuals.

Public health registries are used not just for research but for surveillance activities as well (Teutsch & Churchill, 2000). Cancer registries are perhaps the gold standard of public health registries and have received investment and support from the National Cancer Institute, the Centers for Disease Control and Prevention, and other federal agencies since the 1970s. Unlike cancer registries for which case identification is based on diagnosis of a particular disease, case identification for a disaster registry may be defined as the possible exposure to a known or unknown environmental contaminant, set of contaminants, or posttraumatic stress disorder (PTSD). There is an inherently prospective element to these environmental health registries.

A series of public health responses following the WTC disaster illustrates the challenges of performing surveillance following disasters. This paper examines the methods used by two public health registries: the World Trade Center Health Registry (WTCHR) and the Rapid Response Registry (RRR). We identify lessons learned from establishing the WTCHR and then describe how the RRR incorporated those lessons to begin to address the challenges of surveillance following future disasters.

THE WORLD TRADE CENTER HEALTH REGISTRY

The World Trade Center Health Registry was designed to serve as the comprehensive denominator for persons most acutely exposed to the event. Following the WTC disaster in 2001, the New York City Department of Health and Mental Hygiene (NYCDOHMH) discussed ways to understand the long-term public health effects of the disaster on the various populations in lower Manhattan. NYCDOHMH requested the assistance of the Agency for Toxic Substances and Disease Registry (ATSDR), and in October 2002, ATSDR awarded a contract to RTI International to help establish the registry. RTI International's responsibilities were to perform outreach to and assemble a cohort of potential registrants, to trace them, and to collect data on their possible exposures to the disaster, as well as on their physical and mental health. The WTCHR is intended to be the comprehensive denominator of the persons most acutely exposed to the disaster. RTI International worked with ATSDR and NYCDOHMH to create a list of approximately 200,000 individuals, including rescue, recovery, and clean-up workers; office building occupants; residents; and school children and staff who were closest to the disaster. Recruitment activities commenced in April 2003, almost two years after the disaster and after there had been considerable dispersion of the exposed populations.

Methods Implemented on the WTCHR

Building the sample for the WTCHR was an iterative, multistage process. Outreach—offering potentially eligible individuals a means to enroll via a toll-free number or Web site—and the collection of lists of eligible persons—"list building"—were intensive efforts conducted concurrently for a total duration of 20 months. These three methods, and the synergy between them, were critical to the establishment of the registry. Recruitment began in April 2003, about six months prior to start of WTCHR baseline data collection. The sample-building effort for the WTCHR resulted in the identification of over 2,200 entities across the four sample types pursued and a sample of over 197,952 names of potentially eligible respondents. Of the 197,952 preregistrants identified, 135,553 originated from lists sent to the WTCHR, 36,847 from inbound calls, and 25,552 from Web site self-registrations. Of these, interviews were completed with 71,437 eligible individuals. Each of the three sample-building modes significantly contributed to the total number of completed interviews, with 28,581 originating with an inbound call to the WTCHR, 22,039 from list cases, and 20,817 from Web site self-registrations (Dolan, Murphy, Thalji, & Pulliam, 2006).

Promoting the WTCHR: Community Outreach Campaign

Outreach and media campaigns were mounted during the enrollment phase of the WTCHR to create awareness of the program, encourage cooperation among those called for their interview, and promote self-identification for enrollment. The outreach campaign also attempted to reach hard-to-find individuals who might not appear on lists (e.g., undocumented workers and residents, visitors to lower Manhattan on 9/11/01) and to be accessible to diverse ethnic and cultural groups. A key component of the WTCHR outreach strategy was participation in public forums by representatives of the WTCHR in order to inform key organizations about the WTCHR and address their concerns. Another salient component of the outreach strategy was an advertising campaign with materials tailored to the diverse groups of individuals eligible for enrollment. All outreach materials were translated into Chinese and Spanish, and all materials provided information on the toll-free number and Web site for self-registration.

Providing Registrants a Means to Self-Enroll in the WTCHR

To maximize the number of eligible enrollees, the WTCHR established a toll-free telephone number (1-866-NYC-WTCR) and public Web site (www.wtcregistry.org) to encourage potential registrants to self-identify. The toll-free number was equipped to handle calls from potential registrants in multiple languages; the Web site was accessible in English, Chinese, and Spanish. Information on the toll-free number and Web site was included on all community outreach and registrant materials (e.g., subway posters, brochures, palm cards, lead letters, etc.) and provided potential registrants another means to enroll. The public Web site was opened prior to data collection and allowed potential registrants to pre-enroll by providing their contact information.

Obtaining Lists of Potential Registrants from Eligible Organizations

As part of the list building process, the WTCHR team contacted representatives of eligible entities to explain the purpose of the WTCHR, confirm eligibility, obtain a mailing address to send informational materials, and request a list of potential registrants. The process for identifying eligible organizations and entities to be contacted for lists differed by target population, as follows:

Lists of building occupants. The first step in this process involved defining the universe of businesses in WTC buildings or other buildings retrospectively identified by New York City Department of Buildings as too damaged for occupancy by the WTC attacks on September 11, 2001. The primary source of businesses to be contacted for the WTCHR was a list purchased from a sample vendor. The sample vendor was provided with specifications that included all address permutations and building names for the 38 damaged or destroyed buildings and structures. Business names, contact information as of 9/10/01, and business size were compiled and sent to the WTCHR team. To maximize coverage for businesses, three additional sources of business information prior to 9/11 were identified and obtained. Other published and Internet resources also were used to identify potentially eligible businesses (e.g., CNN, *The Wall Street Journal*, building management lists of tenants).

Lists of workers & volunteers involved in rescue, recovery, & clean-up. Responders to the WTC disaster comprise a diverse and geographically dispersed group. While many companies were found on lists of credentialed or documented responder organizations, many were not and required additional research to identify. Several of the organizations that responded to the WTC disaster are well known and were contacted directly (e.g., FDNY, NYPD, construction companies assigned to the four quadrants of the WTC site). The WTCHR team collaborated with city, state, and federal agency officials, as well as union officials, to compile lists of additional responding organizations and subcontractors. In addition, WTC-related research studies and publications, as well as contacts at St. Paul's Chapel, were consulted for any leads on worker and volunteer organizations active in 9/11 efforts.

Lists of residents. Individuals whose primary residence was south of Canal Street on 9/11/01 were eligible for enrollment in the WTCHR. To develop a sample of residents, RTI International purchased lists of potentially eligible residents from a sample vendor whose primary source of data is Info-USA, which is a compilation of White Pages listings and other public sources. Two lists were purchased based on proximity of residence to the WTC site: (1) residents south of Chambers Street and (2) residents south of Canal Street but north of Chambers Street. These lists were supplemented by lists received from targeted tenant organizations in residential buildings within the eligibility boundaries.

Lists of school students & staff. Students enrolled and staff working at schools or day care centers south of Canal Street on 9/11/01 were eligible for enrollment in the WTCHR. Public and private school data for the 2000–2001 school year are publicly available from the National Center for Education Statistics (NCES). Public school enrollment and staff data are available for all public schools in the catchment area from the Common Core of Data (CCD). Private school data come from the Private School Survey (PSS). Each school in the eligible ZIP codes in lower Manhattan was mapped to determine whether it fell within the catchment area. Preschools and day care centers within the catchment area were identified through information from the NYC Bureau of Day Care.

Of the 2,200 entities identified via the sample-building effort, 1,212 were confirmed as eligible for the WTCHR. During the WTCHR enrollment period, 232 lists representing 135,553 potential registrants were obtained and processed. By target population, 144 lists of rescue/recovery/clean-up workers and volunteers, 76 lists of building occupants, 9 lists of students and school staff, and 3 lists of residents were imported into a database used to manage locating of potential enrollees and interviewing (Dolan et al., 2006). Approximately 73% of the preregistrants believed to be eligible were contacted, and 82% of the cohort cooperated with the WTCHR. In general, the potential registrants from the lists screened into the WTCHR at a relatively high rate; the eligibility rate was 73% (Pulliam et al., 2006).

Lessons Learned from Establishing the WTCHR

The sample-building methods used on the WTCHR were successful; as with any large complex endeavor, however, there were a number of lessons learned from the experience. Although the case ascertainment effort yielded over 197,952 potential registrants with a relatively high eligibility rate, we believe that the effort would have been more efficient if the public health outreach campaign had been rolled out several months in advance of the sample-building task. The list-building task took several months to achieve momentum and to gain acceptance from eligible organizations. Because of the amount of time it took to get the first lists in, activities such as tracing and data collection were delayed.

Another lesson learned relates to the partnerships that an effort of this magnitude requires. The establishment of the WTCHR was a collaboration between three partners that offered unique competencies: The New York City Department of Health and Mental Hygiene offered local knowledge for outreach and helped facilitate a number of crucial contacts for the sample-building team. The Agency for Toxic Substances and Disease Registry offered a depth of experience in establishing registries and in making connections with other federal agencies that responded to the disaster. Finally, RTI International offered competencies in institutional contacting, sample monitoring, and project management. The synergy between these organizations yielded excellent results. Embedded in this multi-organizational approach is another set of lessons learned that are enumerated in a 2005 GAO report.

The 2005 GAO report indicates that funding for the WTCHR was in place in July 2002, but data collection from registrants did not begin until September 2003. There were several sources of this delay. The WTCHR required review by each organization's IRB. Protocol development took longer than expected because of the multi-organizational approach. Questionnaires were developed, programmed, and tested in English, Spanish, and Chinese. The GAO report identifies ATSDR's establishment of the Rapid Response Registry as a best practice stemming from the challenges of establishing the WTCHR.

THE RAPID RESPONSE REGISTRY

Under Emergency Support Function 10 of the National Response Plan, the Department of Health and Human Services is tasked with establishing registries of persons exposed to chemical, biological, radiological, and naturally occurring disasters (Department of Homeland Security, 2004). ATSDR's Rapid Response Registry aims to (1) support real-time needs assessment during an emergency affecting public health; (2) assess future needs for medical assistance, health interventions, and health education for public health planning purposes; (3) contact enrolled individuals with information regarding potential exposures and adverse health impacts, health updates, available educational materials, and follow-up assistance or services; and (4) make contact information available to researchers for future health studies, which are not a part of the Rapid Response Registry (Muravov, Inserra, Pallos, & Blindauer, 2004).

To achieve these goals, the RRR has the ambitious goal of beginning collection of information from exposed individuals in as little as eight hours following the disaster. Because the RRR is intended to be a public health response and not research, it does not require IRB review and therefore avoids one of the sources of delay in establishing the WTCHR.

A key challenge undergirding the design of systems for the RRR was the large number of settings, as well as known and unknown variables that might affect the use of the RRR system—from the type of event, the type of exposures, the locale and populations involved, to the infrastructure affected following a disaster, whether information is collected inside or outdoors, and whether there is electricity and Internet connectivity. Another constraint in designing the RRR was the need to keep the questionnaire form brief—both in terms of the feasibility of collecting information in a dynamic setting as well as the requirement that the RRR collect information to assess public health needs rather than be the comprehensive research project following a disaster.

ATSDR contracted with RTI International to design and test the systems to be used by the RRR including the development of a paper-and-pencil instrument, cognitive interviewing to assess potential respondents' understanding of the survey form, the usability testing of different hardware that might be used by the RRR, and a drill to assess the feasibility of using the RRR tools in a dynamic setting.

The need to deploy the RRR in as quickly as eight hours after acute emergency response settings presented several challenges to developing a draft data collection instrument. One key requirement was that the instrument be short, with an administration time of no more than 10 minutes. Additionally, this one instrument must be able to collect information on a wide range of types of disaster events (e.g., a natural disaster, terrorist attack, chemical spill). It was decided that the instrument would be comprised of predominantly contact information with a few basic exposure measures, since the RRR is designed to initiate registrants in the surveillance process for potential long-term follow-up should exposure be a concern.

Once a draft RRR instrument was developed, three phases of system pretesting were implemented. The first phase was cognitive interviewing. The goal of cognitive interviewing was to identify problems in question wording or format that led to any confusion or response error on the part of participants. The second phase was ausability test of the questionnaire as administered in four different modes. The goals of usability testing were to (1) assess ease of using the data collection instrument by individuals representing the kinds of people who would use the RRR instrument in the field and (2) evaluate which data collection mode would best meet the needs of RRR field data collectors. The third phase of pretesting was a data collection drill. The goal of the drill was to test the general readiness and logistics of RRR systems.

Cognitive Interviewing

Cognitive interviewing was conducted with respondents including Red Cross volunteers, firefighters with EMT experience, and members of the general population. Each participant was administered the RRR questionnaire in person. Concurrently, the interviewer asked scripted and unscripted probes as they determined their answers to questions, with the goal of uncovering discrepancies between what survey designers had in mind and what respondents were actually thinking about while answering. Each participant was asked to volunteer critiques or comments as they were completing the interview.

Since the bulk of the RRR questionnaire was contact information for the registrant and contacts, most participants did not have trouble comprehending the questions. A few changes were made to streamline the instrument for quicker administration, including adding checkboxes to indicate that the proxy's contact information was the same as the registrant's, adding skip patterns so unemployed registrants were not asked about work contact information, and allowing entry of only four digits of the registrant's Social Security number (Dean, 2004a).

Usability Testing

Usability tests were conducted with participants in RTI International's Laboratory for Survey Methods and Measurement. Whereas cognitive interview participants played "respondents" to test the ease of comprehending the questionnaire, usability test participants tested the instrument in the role of the interviewer/data collector, the primary user. Subjects were recruited from populations considered most likely to be mobilized to collect RRR data in response to an event: experienced field interviewing staff, public health workers with a research or clinical background, local health department staff, and Red Cross emergency response volunteers. Usability test participants were given brief instructions and then asked to administer the interview to the test facilitator, who played the role of respondent. Each participant tested only one of four data collection modes: laptop, tablet PC, handheld PC, and paper-and-pencil form.

Participants who used the laptop thought it was very easy to use while seated. They envisioned it being used in a field setting that involved a permanent station where the interviewer would sit at a table, and registrants would come to him or her to be interviewed. It would be nearly impossible to conduct a significant number of interviews while standing and holding the laptop, since the keyboard requires two hands for data entry. Participants did not have trouble entering data into the form on the laptop. They were able to enter data and back up fairly easily.

The tablet PC was less bulky than a laptop and did not require sitting down, but testing showed that it was still cumbersome and too heavy to stand holding for long periods of time. It generated a lot of heat, which might be uncomfortable in the field in a warm setting. Participants had difficulty using the on-screen keypad (activated with a stylus) to enter data. Handwriting data and relying on the software to interpret it was not considered an option due to the importance of getting every letter and number correct for items like the contact information. There were problems with the keypad covering up the questionnaire form, so the user had to go back and forth to refer to the question then enter the answer. On the keypad, participants had difficulty figuring out how to delete text, use the space bar, and use uppercase letters. These would be training issues for interviewers to practice before going into the field.

Response to the handheld PC was generally positive. Participants liked the small size, portability, and the professional look of the tool, even though they thought a paper form might be easier to use. Participants had problems viewing the screen of the handheld PC. The backlight had a tendency to go dark, and the test participants thought that the machine had turned off, rather than having just gone into battery saving mode. Additionally, the text on the small screen was hard to read and especially difficult under the glare of daylight. Moving around into the shade and so that the sun was not behind the user made it a little better, but it was still difficult to see. One participant commented midway through the interview that his hand was cramping from using the stylus. The keypad for the handheld PC caused some challenges as well, mostly due to the need to toggle frequently between a number pad and a QWERTY keypad to enter address data.

Usability concerns with the paper-and-pencil instrument were minimal compared to the other three modes of administration. The most significant challenge of the paper form was the requirement that it fit on one single front and back page for ease of use in the field. All participants had some trouble following the printed skip patterns and reading response categories due to inconsistent formatting. Additionally, one participant thought the paper instrument's filled text (used to tailor proxy and nonproxy interviews) was awkward—he had some trouble determining when to use "you" and when to use "registrant" (Dean, 2004b).

Drill

To assess the systems developed for the RRR, an emergency drill was held in Atlanta in April 2005. The RRR is designed to be scalable, meaning that for some events, ATSDR or CDC staff may perform the data collection without using a data collection contractor. Accordingly, the drill was designed to test ATSDR's ability to download the system onto various hardware prior to data collection. An operations guide detailing the steps necessary to install software on the data collection hardware was used by ATSDR to load the RRR survey instrument on machines prior to the drill.

ATSDR and RTI International held the drill in conjunction with fire drills scheduled at the Centers for Disease Control (CDC) offices at Century Boulevard in Atlanta. Data collectors interviewed CDC staff at three separate building evacuations associated with the fire drills. Data collectors used all modes of survey capture, including handhelds, tablet PCs, laptops, and paper-and-pencil interviews (PAPI). Over 50 interviews were completed. Data collectors manually entered PAPI forms into a Web interview following the drill; data captured electronically were transferred to the central database. Finally, drill data were integrated, and reports were examined to assess completeness and quality of data. The format and utility of the reports themselves, as well as the overall functionality of the case management system, also were considered.

The drill identified minor equipment problems that had been presaged by the usability testing. Data collectors had difficulty reading tablet PC screens in daylight. Handheld PCs were rated highly by drill data collectors, but it was noted that these devices require a greater amount of concentration and thus may result in less interaction with the respondent. An additional lesson learned from the drill was that the installation process on machines that have not been used in prior events cannot be underestimated. To use the survey instrument on the various modes of hardware, the RRR requires enough lead time to properly set up the machines.

Following the drill, a number of modifications were made to the RRR systems. The PAPI and CAI instruments were refined. The operations guide for the systems was updated, and the Web portal used to download the RRR systems was refined and expanded. A number of tasks were identified as next steps for work on the RRR systems. One was an expansion of the training module used for data collectors. The experience of the drill suggested the need for follow-up drills to enhance and maintain readiness for responding to an event. Moreover, the goals of the drills need to be expanded to test the various logistics involved in staffing and responding to an emergency event (Pulliam et al., 2005).

DISCUSSION

The World Trade Center Health Registry and Rapid Response Registry suggest some challenges, lessons learned, possible solutions, and other considerations in attempting to establish and improve new surveillance programs following disasters. The WTCHR shows that with a large heterogeneous population exposed to a disaster, case identification becomes a daunting effort even before one begins to tackle related challenges, such as exposure assessment. The program indicates that thorough, rigorous sample-building methods can be successful. The coverage rate for the WTCHR is defined as "the extent to which the sample frame covers the true eligible population," and the Registry's coverage rate is 33% of the true eligible population of approximately 365,000 individuals (Pulliam et al., 2006). Although this represents a success, especially when considering the size and complexity of the exposed population, the notion of a 33% coverage rate raises questions about whether there are biases inherent in the WTCHR. One approach to addressing this in the future might be to establish a probability-based sample of potentially exposed individuals at the same time one establishes an environmental exposure registry that attempts to enroll all affected individuals. Comparison of the two could allow assessment of whether a public health registry is generalizable.

The Rapid Response Registry is an innovative program that intends to obviate the WTCHR's delays and the inherent costs and other challenges of assembling a complex cohort well after a disaster has occurred. In doing so, the RRR shows that widely used survey methods, such as cognitive interviewing and usability testing, are beneficial to a surveillance program much as they are to refining a probability-based longitudinal study. The RRR also demonstrates the need to use innovative methods, such as a drill, to ensure readiness to initiate a surveillance program following a disaster. In one respect, a drill like the one conducted for the RRR could be considered a "dry run" akin to a pilot test of a survey. It is also important to recognize that the survey research industry can draw on lessons learned from related fields. The disaster research field has institutionalized a number of best practices for ensuring a quick field response to help understand institutional responses to disasters (Tierney, Lindell, & Perry, 2001). Likewise, the emergency response arena has conducted multiple iterations of drills, such as TOPOFF, that may lend lessons learned for some of the logistical challenges of initiating surveillance quickly after an event. The evolving needs for surveillance programs suggest the importance of a flexible approach to health survey research methods.

REFERENCES

Dean, E. (2004a). *Rapid Response Registry (RRR) cognitive interviewing report.* Submitted to the Agency for Toxic Substances and Disease Registry (ATSDR). RTI International.

Dean, E. (2004b). *Rapid Response Registry (RRR) usability testing report.* Submitted to the Agency for Toxic Substances and Disease Registry (ATSDR). RTI International.

Department of Homeland Security. (2004, December). *National response plan.* Retrieved June 26, 2007, from www.dhs.gov/xlibrary/assets/NRP_FullText.pdf

Dolan, M., Murphy, J., Thalji, L., & Pulliam, P. (2006, January). *World Trade Center health registry sample building and denominator estimation.* Research Triangle Institute. Submitted to New York City Department of Health and Mental Hygiene and the Agency for Toxic Substances and Disease Registry.

Muravov, O., Inserra, S., Pallos, L., & Blindauer, K. (2004, June). *Rapid Response Registry (RRR) response plan.* Agency for Toxic Substances and Disease Registry (ATSDR).

Pulliam, P., Dolan, M., & Dean, E. (2005, June). *Rapid Response Registry (RRR) final report.* Submitted to the Agency for Toxic Substances and Disease Registry (ATSDR). RTI International.

Pulliam, P., Thalji, L., DiGrande, L., Perrin, M., Walker, D., Dolan, M., et al. (2006, April). *World Trade Center health registry: Data file user's manual.* RTI International, New York City Department of Health and Mental Hygiene, and the Agency for Toxic Substances and Disease Registry.

Tierney, K., Lindell, M., & Perry, R. (2001). *Facing the unexpected: Disaster preparedness and response in the United States.* Washington, D.C: Joseph Henry Press.

Teutsch, S., & Churchill, R.E. (2000). *Principles and practice of public health surveillance.* New York: Oxford University Press.

U.S. Government Accountability Office (GAO). (2005). *September 11: Monitoring of World Trade Center health effects has progressed, but not for federal responders* (GAO-05-1020T). Testimony before the Subcommittee on National Security, Emerging Threats, and International Relations, Committee on Government Reform, House of Representatives. Washington, DC: Author.

FEATURE PAPER: The Electronic Data Capture System Used to Monitor Vaccines during the U.S. Army's Smallpox Vaccination Campaign

Judith H. Mopsik, *Abt Associates, Inc.*
John D. Grabenstein, *Merck & Co., Inc.*
Johnny Blair, *Abt Associates, Inc.*
Stuart S. Olmsted and Nicole Lurie, *RAND Corporation*
Pamela Giambo, *Westat*
Pamela Johnson, *Voxiva, Inc.*
Rebecca Zimmerman, *RAND Corporation*
Gustavo Perez-Bonany, *Voxiva, Inc.*

BACKGROUND

The attack on the World Trade Center and Pentagon on September 11, 2001, along with the subsequent anthrax attacks via the U.S. Postal Service, raised concerns about the release of weaponized smallpox virus (i.e., variola virus), both domestically and among U.S. interests abroad. This led the U.S. government to decide to vaccinate selected military personnel, first responders, and public health workers against the disease. However, the use of the smallpox (i.e., vaccinia) vaccine entailed some measure of uncertainty: much of the U.S. population was naïve to smallpox, and the rate of contraindications for the vaccine had risen in the last 30 years because of increased prevalence of certain forms of cancer, HIV/AIDS, other reasons for immunosuppression and eczema (Centers for Disease Control and Prevention [CDC], 2002b). The amount of increase in such contraindications is unknown.

In November 2002, the CDC issued the *Smallpox Response Plan and Guideline* (Version 3.0; 2002a). This plan called for active surveillance for adverse events. Vaccine recipients would be provided with a (paper) diary report card to document their response to the vaccine (Exhibit 1).

There were concerns about the validity of information provided with paper diaries. Earlier studies reported that patient compliance with paper diaries is low (as low as 11%), and subjects frequently complete their paper diary cards retrospectively. In one study, one third of the patients forward-filled their diary entries, resulting in an unknown amount of increased reporting error. By contrast, patients using electronic diaries were 93% compliant with the study protocol and entered their data in real time (Stone, Shiffman, Schwartz, Broderick, & Hufford, 2002). As the Department of Defense began its plans to vaccinate military and accompanying civilian personnel in advance of deployment to Iraq, the limitations of paper-based systems caused several concerns.

1. To be useful, diary data would need to be transcribed laboriously into an electronic database, and already the paper diaries of early vaccinees were accumulating.
2. Paper diaries did not allow for concurrent monitoring. It would not be possible due to the

lag in receipt and entering of data from paper forms. Consequently, data would not be accessible by medical personnel on a sufficiently timely basis.

3. Self-report of vaccination site appearance and symptoms, if clinically accurate, could potentially provide an indicator of successful vaccination, early warning of adverse reactions, and obviate the need for a post-vaccination check with a health care provider.

For self-reporting to be acceptable, the DOD needed to have a suitable method of closely monitoring vaccinees in near-real time to enhance the safety for vaccine recipients and their contacts. Large-scale data on adverse events after smallpox vaccination were more than 30 years old and reflected none of the significant improvements in data collection that had occurred subsequently (Altman, 2002).

Exhibit 1. Smallpox Vaccine Adverse Event Diary Report Card

Symptom(s) New onset following vaccination	**DAY POST VACCINATION** Please note that the day of vaccination is denoted as Day 0 and others numbered sequentially																					Week 4 (Days 21–27)
	0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**	**18**	**19**	**20**	
Day scab fell off:																						
No symptoms																						
Fever (Record temperature)																						
Chills																						
Joint pain																						
Muscle pain																						
Fatigue																						
Loss of appetite																						
Cough																						
Swelling/tender lymph nodes																						
Itching on body																						
Headache																						
Backache																						
Abdominal pain																						
Difficulty breathing																						

INTRODUCTION

In 2002, concerns about the release of weaponized smallpox virus led the U.S. government to vaccinate selected military personnel, first responders, and public health workers against the disease. As already noted, at that time, the use of the vaccine entailed some measure of uncertainty, since most of the U.S. population younger than 30 years of age was naïve to smallpox and the rate of contraindications for the vaccine had risen in the last 30 years. For these reasons, close monitoring was essential to enhance safety for vaccine recipients and their contacts.

Abt Associates, Inc. and Voxiva, Inc. collaborated to develop a smallpox vaccine monitoring system for the Military Vaccine Agency of the Department of Defense. This telephone/Internet-based system allowed detailed self-reporting of clinical response to smallpox vaccination by vaccinees and provided for the active monitoring and analysis of events associated with administration of the vaccine. A convenience sample of 1,780 military and civilian personnel vaccinated between March and November 2003 participated in this study. Participants were requested to maintain an electronic diary of their signs and symptoms at the vaccination site and of their overall well-being for up to 28 days following vaccination.[Note 1]

Data gathered from this sample could provide early insight into adverse reactions and other concerns. Accurate monitoring would provide a thorough record of normal reports as well as estimates of the number and type of adverse events likely to be experienced by vaccine recipients. If recipients were able to report their own cutaneous responses ("vaccination takes") reliably, this would facilitate large-scale vaccine administration, especially among dispersed groups such as reserve personnel or geographically isolated troops.

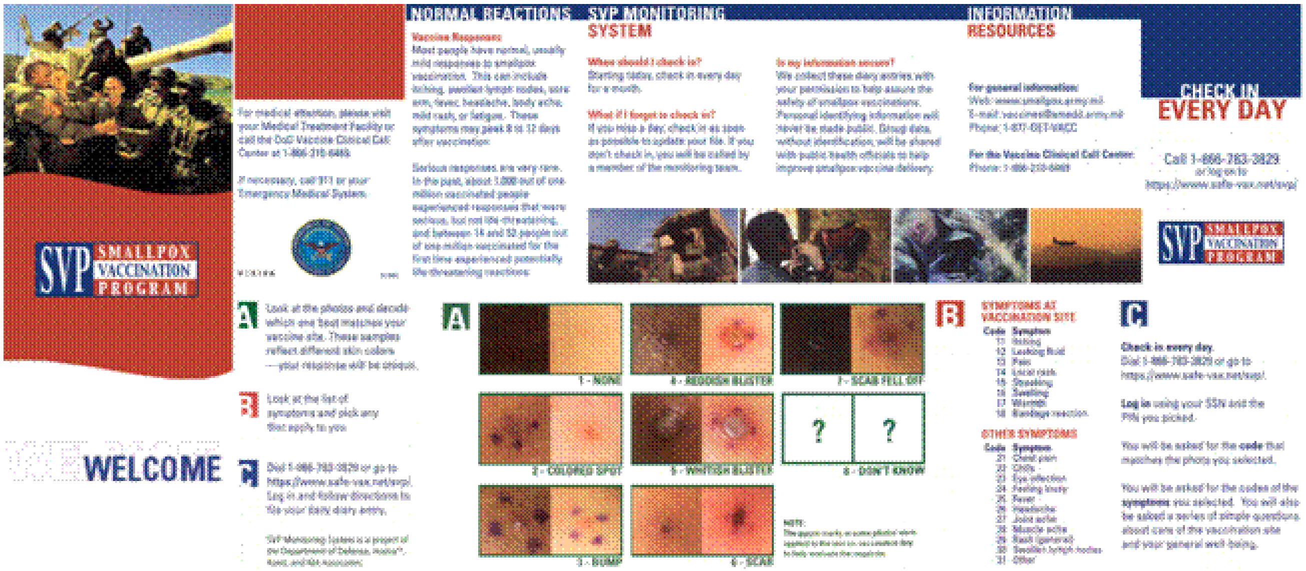
In summary, the objectives of the project were to

- Provide concurrent monitoring of recipients of the smallpox vaccine to describe signs and symptoms after vaccination;
- Work with program evaluators to determine the feasibility (i.e., human factors) and benefits of active electronic surveillance;
- Assess concordance of self-assessment of vaccination response with that of a trained health provider; and
- Guide the possible larger DOD rollout of an electronic vaccination-monitoring program.

METHODOLOGY

A multimode reporting system combining the Web and phone-based data entry over a secure network had been developed by Voxiva, Inc. as a disease reporting system for public health officials and Peruvian and American naval medical officials. Customizing this system for the smallpox application allowed vaccine recipients to submit daily reports from any telephone or Internet-connected device worldwide. Messaging functions provided system administrators with the ability to issue alerts to vaccine recipients or clinic medical directors, and a trigger notification system alerted administrators and medical directors via e-mail, telephone, or SMS text message when key events, such as specific severe reactions, occurred. Abt Associates adapted traditional survey data collection methods for questionnaire design and pretesting, Web usability testing, enrollment, data collection, and follow-up for nonresponse. Since the completion of the Smallpox Vaccine Project, this system has been adapted to monitor blood shortages, to conduct syndromic surveillance, and for other public health applications.

Exhibit 2. Wallet-Size Instruction Card



SVP SMALLPOX VACCINATION PROGRAM

WELCOME

For medical attention, please visit your Medical Treatment Facility or call the DoD Vaccine Clinical Call Center at 1-866-210-6469.

If necessary, call 911 or your Emergency Medical System.

NORMAL REACTIONS

Vaccine Responses:
Most people have normal, usually mild responses to smallpox vaccination. This can include itching, swollen lymph nodes, sore arm, fever, headache, body ache, mild rash, or fatigue. These symptoms may peak 8 to 12 days after vaccination.

Serious responses are very rare. In the past, about 1,000 out of one million vaccinated people experienced responses that were serious, but not life-threatening, and between 14 and 52 people out of one million vaccinated for the first time experienced potentially life-threatening reactions.

SVP MONITORING SYSTEM

When should I check in?
Starting today, check in every day for a month.

What if I forget to check in?
If you miss a day, check in as soon as possible to update your file. If you don't check in, you will be called by a member of the monitoring team.

Is my information secure?
We collect these diary entries with your permission to help assure the safety of smallpox vaccinations. Personal identifying information will never be made public. Group data, without identification, will be shared with public health officials to help improve smallpox vaccine delivery.

INFORMATION RESOURCES

For general information:
Web: www.smallpox.army.mil
E-mail: vaccines@amedd.army.mil
Phone: 1-877-GET-VACC

For the Vaccine Clinical Call Center:
Phone: 1-866-210-6469

CHECK IN EVERY DAY

Call 1-866-783-3829
or log on to
https://www.safe-vax.net/svp/

SVP SMALLPOX VACCINATION PROGRAM

A Look at the photos and decide which one best matches your vaccine site. These samples reflect different skin colors —your response will be unique.

B Look at the list of symptoms and pick any that apply to you.

C Dial 1-866-783-3829 or go to https://www.safe-vax.net/svp/. Log in and follow directions to file your daily diary entry.

"SVP Monitoring System is a project of the Department of Defense, [illegible]

A

1 - NONE
4 - REDDISH BLISTER
7 - SCAB FELL OFF
2 - COLORED SPOT
5 - WHITISH BLISTER
8 - DON'T KNOW
3 - BUMP
6 - SCAB

NOTE:
[illegible] applied to the skin on vaccination day to help evaluate the response.

B SYMPTOMS AT VACCINATION SITE

Code	Symptom
11	Itching
12	Leaking fluid
13	Pain
14	Local rash
15	Streaking
16	Swelling
17	Warmth
18	Bandage reaction

OTHER SYMPTOMS

Code	Symptom
21	Chest pain
22	Chills
23	Eye infection
24	Feeling lousy
25	Fever
26	Headache
27	Joint ache
28	Muscle ache
29	Rash (general)
30	Swollen lymph nodes
31	Other

C

Check in every day.
Dial 1-866-783-3829 or go to https://www.safe-vax.net/svp/.

Log in using your SSN and the PIN you picked.

You will be asked for the **code** that matches the photo you selected.

You will be asked for the codes of the **symptoms** you selected. You will also be asked a series of simple questions about care of the vaccination site and your general well-being.

When participants came to the clinic for their smallpox vaccination, they were invited to participate in the electronic diary system, as previously described (Olmstead et al., 2005; Olmstead, Grabenstein, Jain, & Lurie, 2006). They were provided with a briefing kit consisting of a consent form and educational materials. After vaccination, they attended a brief video about smallpox vaccination and received a wallet-size instruction card listing possible symptoms (Exhibit 2). Participants were instructed to report daily by Web or phone, regardless of the presence of symptoms: the lack of occurrence of symptoms was important information in calculating incidence rates. On the back of the card were progressive photos of the expected appearance of a smallpox vaccination site, against which individuals could measure their own response. They were instructed to report if they visited a physician or hospital for care for any adverse vaccine reactions.

Each time participants accessed the system to report about the vaccination site and how they were feeling, they also were asked to report any illness among family members. Any reported illness consistent with contact transfer of smallpox virus would be reported immediately to the clinic's medical director for rapid follow-up by a trained health officer.

On post-vaccination days 6–8, each person was instructed to report whether their vaccine site resembled the picture on the card, as well as return to the clinic to have their vaccination site assessed in-person at the clinic where they were vaccinated.

To enhance reporting compliance, specially trained call center interviewers called nonreporting vaccine recipients at several milestones (on the 4th, 7th, and 10th days following vaccination) to obtain data on their well-being and any vaccine reactions. The data collected during these follow-up contacts were entered into the database at the time of the call. All data were immediately available to clinic and supervisory officials monitoring the program. To further enhance compliance, we used specially prepared e-mail messages and telephone system recorded reminders.

Exhibit 4. Vaccinee Description of Vaccination Sites

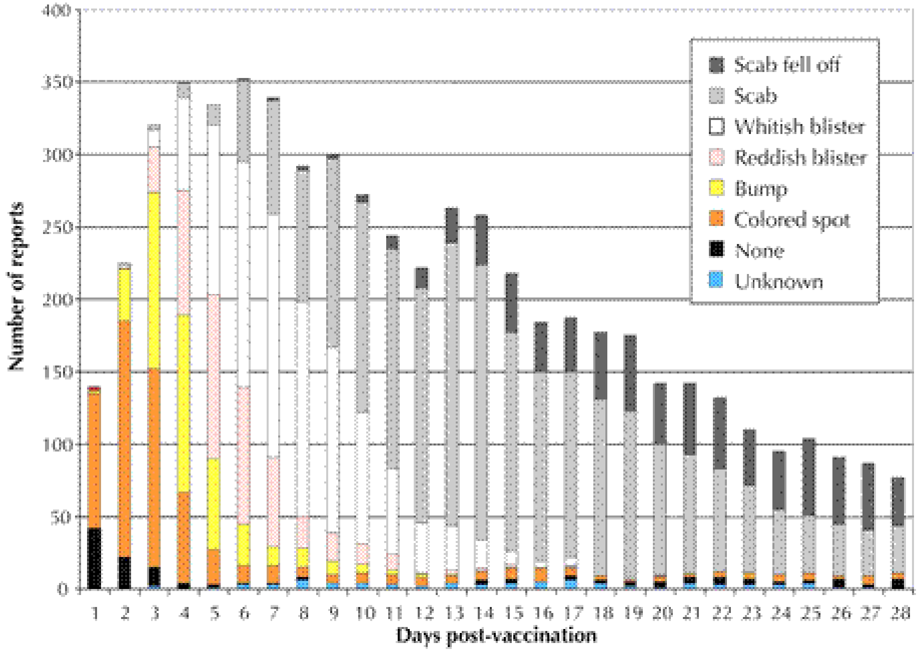
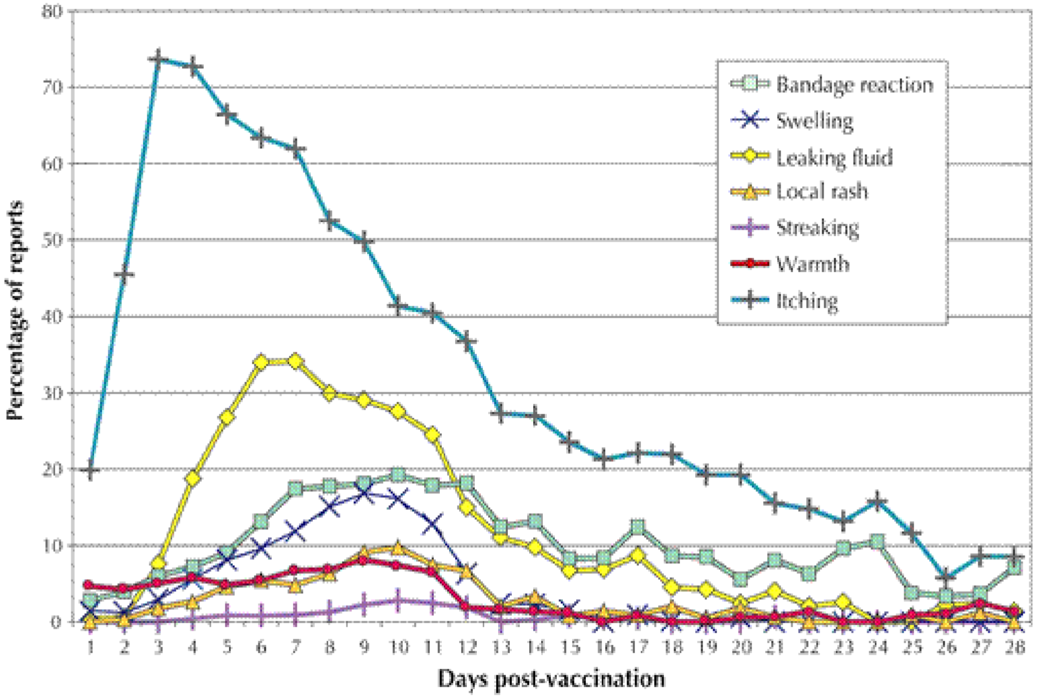
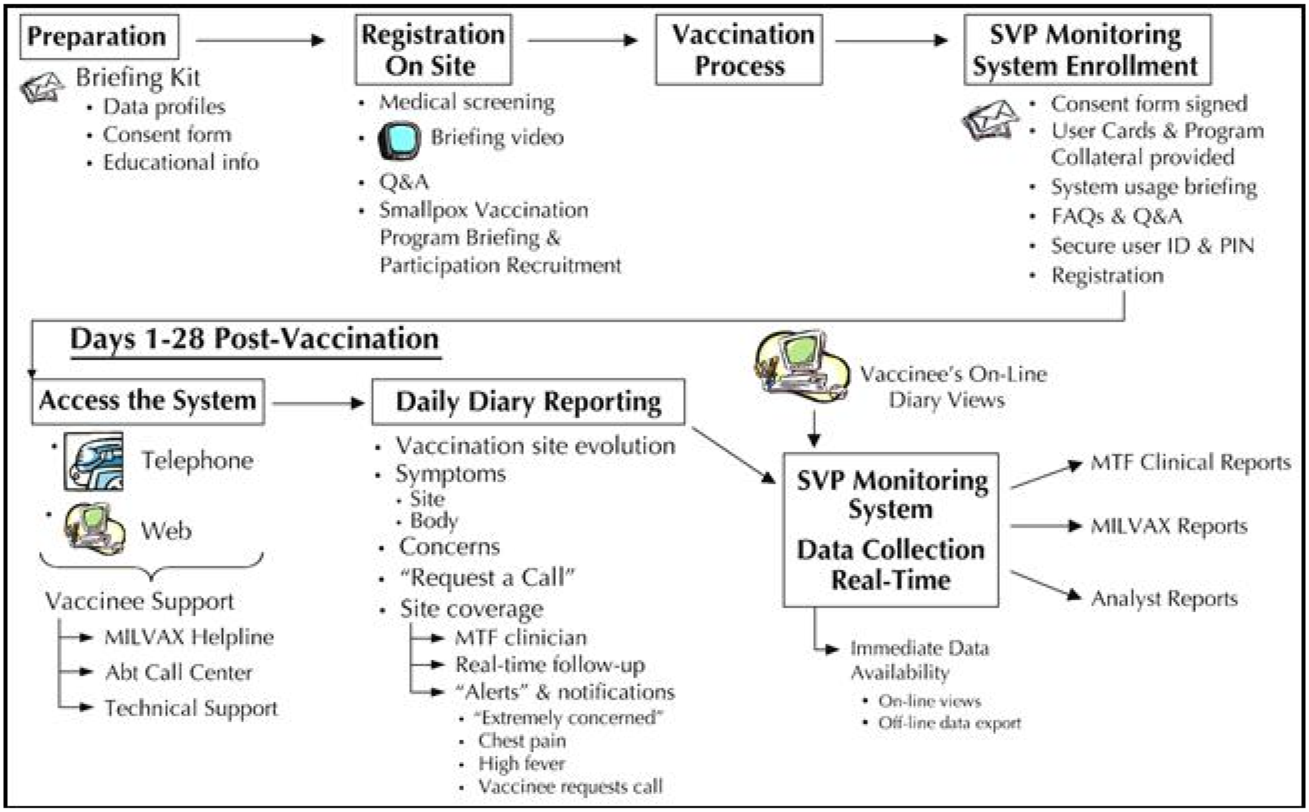


Exhibit 3. Percentage of Reports Describing Local Symptoms



Real-time data gathered about the vaccine's effects provided a thorough record of expected events along with the number and type of adverse events experienced by vaccinees. The adverse event information was monitored in real time by trained staff. Preprogrammed analyses (Exhibits 3 and 4) were run daily to detect any patterns of adverse reactions. Any adverse events were addressed immediately to enhance the safety of military personnel and their families and to prepare our armed forces for deployment as rapidly as possible. These self-reported data, combined with other records, provided data to guide policy and planning for any future widespread vaccination program. The process flow is presented below.



FINDINGS

The system demonstrated that a surveillance system could be deployed within a matter of weeks that would serve the needs of the Military Vaccine Agency to monitor reactions and, at the same time, reassure vaccinees that the health and well-being of them and their families were being closely monitored.

Participants described the response card as easy to understand and reported that both the Web and phone systems were easy to access.

- Real-time rapid identification of possible reactions experienced by individuals or associated with specific vaccine lots or vaccine administration sites was easy to implement using the system.

- Most users (84%) were comfortable with a physician tracking their vaccine reaction using their electronic reports, but only half (51%) were comfortable with eliminating the post-vaccination follow-up visit with their health-care provider based on their electronic reports.
- The system could be deployed and accessed from any location with an electronic connection.
- The automatic alert and notification capabilities served to support both the clinicians and vaccinees.
- Accurate, timely statistics on post-vaccination reactions were monitored daily.
- The Military Vaccine Agency received complete daily documentation and records of adverse events reported following vaccine administration.

The electronic monitoring system was implemented during the preparation for the assault on Iraq. While many thousands of people came to the participating clinics for their vaccinations, only 1,780 people who received the vaccine at four sites volunteered to participate in the system. Many people could not participate in the study because they were deploying within a week and would be unable to fully participate. Volunteers were located at four sites where we conducted the surveillance: Fort Belvoir, Fort Bragg, Fort Hood, and the Pentagon.

Reporting Compliance

The mean number of reports submitted per vaccinee was 6.9. Seventy-two percent of the vaccinees submitted at least one report, and half of those submitting reports submitted five or fewer. Of the 13.7% of the people who only reported one time, 84% of them only reported through the call center.

The sample represented a broad-based population of both civilian and military personnel, and reporting compliance varied by demographics. The five groups with the highest compliance included those age 45+ (80.6%), females (78.5%), officers (77.2%), civilians (77.1%), and Whites (72.5%). Compliance was lowest among those age 18–24 (75.2% did not report), the enlisted (63.3%), Army vaccines (66.4%), and active duty vaccines (68.7%). [Note 2]

About 67% who reported said they had symptoms on their first day of reporting. The later vaccinees submitted their first reports, the more likely they were to report having a symptom at first report. All first reports submitted nine days or more after vaccination included at least one symptom.

The Effect of Callbacks

Nonresponse follow-up calls had a strong effect on reporting: 82% of those who were locatable reported. Accessibility by telephone was the major influence on locatability. Army vaccinees were 40% more locatable than those in other service branches.

EVALUATION

An external assessment of the system was conducted by the RAND Corporation. There were three components to the evaluation: system use, reliability and validity of self-reported takes, and user experience and satisfaction. The evaluation of the validity and reliability of the self-assessment of the vaccination-site information concluded that during a mass vaccination event, an electronic monitoring system could facilitate tracking of vaccine response, provide an early warning system for adverse events, and might reduce the burden associated with follow-up visits with health care professionals (Olmstead et al., 2005, 2006).

Overall, use of the electronic monitoring system was modest, but the sensitivity and positive predictive value of self-report of a vaccine take was quite high. Vaccinees were focused more on deployment and the impending war than on their vaccination. The use of the call center was important in stimulating reporting, although it did not have the magnitude of effect we had hoped. It was expected that the call center prompting would encourage a person to use the electronic diary, but this was not the case. However, based on the results of this demonstration (as noted above), we are able to identify groups at highest risk of not reporting and could target specific subpopulations in future studies for intensive work by the call center.

CONCLUSIONS

This electronic monitoring system was well received by vaccinees and allowed health care providers to track the status of vaccinees. However, vaccinees were not comfortable replacing a physician visit with electronic monitoring, at least for the smallpox vaccination. A monitoring system like this may be useful in public health settings, such as mass vaccination or prophylaxis during a bioterrorism event, a pandemic influenza outbreak, or another public health emergency, because it could facilitate tracking of vaccine reactions, including providing an early warning system for adverse events, and might reduce the burden associated with follow-up visits with health care professionals. However, implementing a tracking system during a wartime build-up is difficult. Service member priorities are necessarily focused on their families and the pending deployment. Service members have many competing priorities, and monitoring their vaccination is not at the top of the list.

REFERENCES

Altman, L. K. (2002, October 18). Close monitoring is planned for smallpox vaccinations. *The New York Times*, p. 11.

Centers for Disease Control and Prevention. (2002a). *CDC smallpox response plan and guidelines, Version 3.0.* Retrieved May 17, 2007, from www.bt.cdc.gov/agent/smallpox/response-plan/index.asp

Centers for Disease Control and Prevention. (2002b, September 23). *CDC telebriefing transcript: MMWR updated smallpox response plan and guidelines.* Retrieved May 17, 2007, from www.cdc.gov/od/oc/media/transcripts/t020923.htm

Olmsted, S. S., Grabenstein, J. D., Jain, A. K., Comerford, W., Giambo, P., Johnson, P., et al. (2005). Use of an electronic monitoring system for self-reporting smallpox vaccine reactions. *Biosecurity and Bioterrorism, 3,* 198–206.

Olmsted, S. S., Grabenstein, J. D., Jain, A. K., & Lurie, N. (2006). Patient experience with, and use of, an electronic monitoring system to assess vaccination responses. *Health Expectations, 9,* 110–117.

Stone, A. A., Shiffman, S., Schwartz, J. E., Broderick, & Hufford, M. R. (2002). Patient non-compliance with paper diaries. *British Medical Journal, 324,* 1193–1194.

[Note 1]Total number vaccinated through October 2003 was 501,946.

[Note 2] These are overlapping categories.

FEATURE PAPER: Conducting Real-Time Health Surveillance during Public Health Emergencies: The Behavioral Risk Factor Surveillance System Experience[Note]

Michael W. Link, Ali H. Mokdad, and Lina Balluz
National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention

INTRODUCTION

Health tracking or "surveillance" in health emergencies is essential for all public health efforts, including decision making as the public health event unfolds; effective allocation of staff, material, and financial resources; and shaping of messages to keep the public informed. Ongoing health surveillance also can aid national, state, and local officials and health professionals in preparing for future crises, identifying potential health problems, planning and evaluating responses, and targeting resources toward populations with the greatest potential needs.

Domestic and international events of the past few years have highlighted U.S. vulnerability to natural disasters such as hurricanes or earthquakes, terrorist attacks with biological and other weapons of mass destruction, and large-scale breakdowns in the public health system, such as widespread shortages of vaccines. Obtaining critical information on the health needs of the population is essential for both effective preplanning and timely post-event response to health emergencies. For instance, growing concern about a future influenza pandemic, underscored by the U.S. government's multibillion-dollar funding proposal for pandemic planning, highlights the need for valid and reliable public health data to inform program planning and evaluation, resource allocation, and real-time action steps (Schmalfeldt, 2005). The Centers for Disease Control and Prevention (CDC) has taken the lead in improving national, state, and local preparedness and in coordinating the effort to upgrade national public health capability to confront the critical public health issues that arise during and after these types of events. An effective response requires an efficient, on-going surveillance system be in place to provide needed information.

The Behavioral Risk Factor Surveillance System (BRFSS) is a premiere health surveillance system operating in all states, more than 100 cities and counties, the District of Columbia, Puerto Rico, Guam, and the Virgin Islands (Mokdad, Stroup, & Giles, 2003). This unique state-based system is the primary source of information on health risk behaviors, preventive health practices, and health care access for state and local policy makers and public health professionals. The BRFSS is a cross-sectional telephone survey conducted by the state health departments with assistance from CDC. The survey has a multistage design that uses random-digit-dialing methods to select a representative sample from each state's noninstitution-alized civilian population age greater than 18 years. The BRFSS is a flexible system, allowing states to add timely questions to the survey to address urgent health issues. As one of the world's largest ongoing health surveys, with more than 350,000 interviews conducted annually, the large sample size, wide geographic coverage, and ongoing monthly data collection cycle make the BRFSS an excellent vehicle for collecting vital information for preparedness planning and nearly real-time health surveillance during public health emergencies.

Many states and cities have used the BRFSS to collect emergency response data. For example, New York, New Jersey, and Connecticut measured the psychological and emotional effects of the September 11, 2001, terrorist attacks on the World Trade Center (CDC, 2002); California evaluated earthquake emergency preparedness; and Connecticut examined the spread and prevention of the West Nile Virus (CDC, 2003).

The objective of this article is to demonstrate how the BRFSS was used to provide needed information during a recent health emergency: the 2004–2005 influenza vaccine shortage. BRFSS was used to monitor influenza vaccine coverage and to gather data that helped inform vaccine redistribution efforts and shape public health messages. Like any survey, however, the BRFSS design, data collection infrastructure, and contract support mechanisms can impose some constraints and challenges in using the system during emergencies. We discuss some of these key successes and challenges, noting how these "lessons learned" can help public health officials plan for effective surveillance during the next public health emergency.

CASE STUDY: THE 2004–05 INFLUENZA VACCINE SHORTAGE

During the 2004–2005 influenza season, the supply of vaccine to the United States was unexpectedly and significantly reduced because of problems with vaccine production. In response, the Advisory Committee on Immunization Practices (ACIP) and CDC recommended vaccination only for persons who were at high risk of influenza-related complications and for certain contacts of high-risk persons; healthier adults were asked to defer or forgo vaccination (CDC, 2004a). Adults were included in the high-risk group if they had any of the following conditions: diabetes, asthma or other lung disease, heart disease, weakened immune system, kidney disease, sickle cell anemia or other anemia, and pregnancy. The same high-risk criteria were used for children, with the exclusion of pregnancy and the addition of those who used chronic aspirin therapy. Because of the high vulnerability of elderly persons and others in the priority groups to complications of influenza, it was important to establish a rapid response surveillance system whereby this vaccination strategy could be monitored as the influenza season progressed and could be modified if necessary.

To track vaccine coverage among these priority groups as the season progressed, a module of

17 questions was developed and administered in all 50 states and the District of Columbia as part of the BRFSS (CDC, 2004b). Before November 1, 2004, influenza vaccination among adults was determined with the question: "Have you had a flu shot/flu spray in the past 12 months?" but no information was collected on the specific month of vaccination or on influenza vaccination among children. Beginning November 1, 2004, new questions were temporarily added to the BRFSS to obtain information on vaccine use in all persons age six months or younger, including month and year of vaccination, whether the respondent was in one of the groups prioritized for vaccination this season, and the reason for not being vaccinated. Priority groups included those age 6–23 months or greater than 65 years; high-risk persons age 2–64 years, including pregnant women; health care workers with patient contact; and adult household contacts of infants age less than 6 months. Vaccination coverage was estimated for adults and children (age 6 months–17 years) as the season progressed. Information was obtained for one randomly sampled adult and one randomly sampled child (if a child or children lived in the household).

States submitted their completed interviews to CDC on a weekly rather than the usual monthly basis. Automated processing and weighting systems provided analysts with clean data sets within three business days, facilitating rapid dissemination of results. Data from interviews were adjusted to account for differential probabilities in the sample selection, the age- and sex-specific population estimates from the 2003 census projections for each state, and the size of the state population.

Data on influenza vaccination coverage from September 1 through November 30, 2004, not quite halfway through the influenza season, suggested that persons in influenza vaccine priority groups were receiving vaccine at higher rates than persons in nonpriority groups, which was in accordance with the ACIP-recommended guidelines (CDC, 2004b). The BRFSS also showed substantial geographic differences in vaccination coverage.

These midseason estimates, however, also showed that a significant portion of the adults in priority groups—particularly those age 65 and older—were not receiving vaccination and appeared to have given up trying to obtain a vaccination. After determining that sufficient supplies of vaccine were still available to meet the projected demand (by analyzing the previous season's vaccination coverage) among those in the priority groups, CDC-sponsored media messages and public service announcements strongly encouraged those in priority groups to obtain vaccination. Further, to ensure that all available vaccine was used, state and local public health officials were authorized to recommend limited expansion of vaccination eligibility in their areas once they determined that all persons in priority groups who were seeking vaccine had received vaccination and that additional vaccine was on hand. In such cases, state or local officials could offer vaccination to persons such as those age 50 to 65 years, household contacts of persons in priority groups, or other populations considered at increased risk. By season's end, the vaccination coverage among adults in most priority groups was just under that of the previous non-shortage season, and although there were racial/ethnic disparities in coverage, the magnitude of those disparities was not much greater than seen in previous years (CDC, 2005; Link et al., 2006).

In sum, the BRFSS was used successfully during the 2004–2005 influenza vaccine shortage to provide federal and state and, in some instances, local decision makers with critical information about vaccine coverage. These data were among several pieces of information used to evaluate the effectiveness of the ACIP priority recommendations, identify areas and key subgroups where vaccine coverage was low, assist in decisions regarding the redistribution of limited vaccine supplies, and develop public health messages encouraging persons in priority groups to seek vaccination.

ELEMENTS FOR SUCCESSFUL CONDUCT OF RAPID RESPONSE SURVEILLANCE

As this case study highlights, ongoing surveillance efforts can provide necessary information for public health decision makers during a health emergency. Whether this be a widespread phenomenon, such as a pandemic or a shortage of essential medical vaccine or supplies, or the aftermath of a terrorist attack or natural disaster, such as a hurricane, this information can help officials redirect resources to critical areas or groups and develop public service messages to keep the public informed and encourage desirable behaviors (such as seeking vaccination or treatment). Many factors contributed to the success of this monitoring effort:

Recognition of the Importance of the Effort

All involved in this effort, from the federal agency staff, those in the states, and the data collectors, considered it important, and the goals of the effort were effectively communicated to staff at all levels. Conducting effective rapid response surveillance requires efforts above and beyond those of routine surveillance. As a result, those involved often needed to work a greater number of hours and complete tasks in a shorter time than normally would have been the case. Working quickly, however, also means that greater care is required in overseeing each step of implementation. This is best accomplished when those involved feel that the effort is important and worthwhile. Effectively communicating the purpose and goals of the effort is critical for motivating staff at all levels of the project.

Understanding of Decision Makers’ Data Needs

Understanding the types of information most important to decision makers is another critical element for quick implementation of health surveillance. Because development of the questionnaire is one of the first critical path components in the deployment of a rapid response system, decision makers must quickly reach an agreement (if not consensus) about which pieces of information are required to effectively manage the situation. In the case of the vaccine shortage, it was relatively quick and easy to determine that monitoring vaccine coverage and adherence to the new ACIP guidelines was essential.

Flexibility of the Data-Collection System

The movement to a rapid response mode is easier if the data collection system is flexible. Questions addressing the rapid response topic must be added to the instrument, and placement and wording of these questions must be considered carefully. The BRFSS questionnaire is already very flexible and includes a standard core of questions for all states, optional standardized modules that states may choose to adopt, and state-added questions particular to each state's needs. Moreover, the BRFSS always has maintained the capacity to add questions on health issues that might emerge during the year. Therefore, the system infrastructure accommodates the addition of new questions, and the computer-aided telephone interviewing systems and data collectors also are primed for such action.

Automated Processing & Weighting of Data

Automation is the key to quick turnaround times. Processes such as file uploading and downloading, data cleaning and quality control, and data weighting can all be automated, which significantly reduces the time between the end of data collection and the start of data dissemination. The BRFSS infrastructure provides automation along these lines, which reduced considerably the amount of time required for data processing and validation.

Standard Web-Based Reporting System

Automated Web-based reports provide end users and decision makers with quick, easy access to the most recent data available. While monitoring the influenza vaccine shortage, BRFSS staff developed a standard set of reports with overall prevalence estimates as well as breakdowns by key demographic groups. Reports were generated at a national and state level, and federal and state epidemiologists had Web-based access to both the reports and weighted data files as soon as processing was completed. With access to both the standardized reports and the actual data, health officials could conduct more detailed analyses as they saw fit.

LIMITATIONS IN CONDUCTING RAPID-RESPONSE SURVEILLANCE

Changes in survey design or questionnaires to affect rapid collection of public health data may, however, lead to tradeoffs between meeting the goals of the ongoing system and those required for rapid response surveillance.

Survey Design Constraints

The extent to which the design of an ongoing survey can be modified rapidly and effectively will determine how effectively that survey can be used for rapid response data collection. Ideally, the ongoing survey would already be collecting the type of information required in the areas and from the populations of interest and within the timeframe required for those data to be acted upon. However, this is almost never going to be the case. Ongoing surveys are designed to address and monitor particular aspects of public health in specific populations. The vaccine shortage highlights just one set of conditions health officials may face during a crisis. The shortage was nationwide in scope; however, it did not involve disruption of the telecommunication infrastructure. Health surveillance by telephone was, therefore, a viable option for reaching the vast majority of the public. In contrast, health surveillance in the wake of the devastating 2005 hurricanes was more problematic in that large populations were displaced from their homes, many to shelters or other locations with no access to a landline household telephone. Moreover, in the early days and weeks after the storms, tens of thousands of households had no electricity or a working landline. As a result, health surveillance conducted by telephone in the wake of the hurricanes was restricted to households where telephone service was working or had been restored. Other surveillance approaches were required to obtain information from those with no telephone access.

Weighting & Post-survey Adjustment Challenges

Survey data typically are adjusted after data collection to correct for probabilities of selection, potential nonresponse bias, and other factors that may introduce bias into the estimates. Likewise, the data often are weighted to the size of the population in a given geographic area so that the incidence of health risks and behaviors can be estimated. Therefore, use of an ongoing system for monitoring a particular area, timeframe, or population usually will require adjustments to the weighting methodology used. Typically, as in the case of the influenza vaccine shortage, this is not a difficult process because population totals exist and weights can be recalibrated as needed. The task is much more difficult, however, when large populations are displaced, as occurred after the hurricanes of 2005. In these instances, no accurate population counts may exist, particularly if the displacement is widespread across the U.S., as it was for the hurricane victims. In these cases, the analyst must either weight the data to pre-event population totals or make some form of adjustment to those totals with the use of available external data (for instance, information from the Federal Emergency Management Agency detailing the number of claims by displaced persons).

Tradeoff of Flexibility & Turnaround Time with Quality & Accuracy

Quick turnaround for survey estimates often comes at the price of shorter-than-usual field periods and faster quality checks. Normally, samples in the BRFSS are fielded for an entire month before the data are finalized. During the 2004–2005 influenza season, however, data were pulled weekly each month to provide interim estimates. These estimates were used to monitor vaccination coverage among those in priority groups and to determine follow-up actions, such as public service announcements and, to a degree, vaccine redistribution efforts, particularly at the state level. However, pulling data early had two effects. First, response rates were lower than those normally reported on a monthly basis. For example, the median state-level response rate for the December 2005 mid-month data was 38.2%, compared with 51.1% at month's end (unpublished data). Although recent studies have found response rates to be a poor proxy for data quality, the lower rates do indicate a higher potential for nonresponse bias in the final estimates (Groves, 2006; Keeter, Miller, Kohut, Groves, & Presser, 2000.

Unclear Information Needs of Decision Makers

It is easy to understand that policy makers and health officials require information to help with decision making, but it is less clear what information they require. In the case of the vaccine shortage, decision makers needed to monitor vaccine coverage, but among which subgroups and at what geographic level? Monitoring public health in the aftermath of the hurricanes was even less clear: Should the focus be on the physical or emotional needs of those affected? In both instances, what additional information was needed to promote an effective public health response? One key decision involves differentiating information that is "essential to know" versus "nice to know"—that is, identifying information that is critical for decision making versus information that might be academically interesting but is not necessarily actionable. Identifying potential information needs for different scenarios during the planning stages before a health emergency and then pretesting these questions can save considerable time and allow faster implementation in the field. The questions developed during the vaccine shortage now serve as a template for monitoring similar shortages in the future. Policy makers would be well served to develop similar modules to have on hand for other potential health crises.

Information Overload

Although the BRFSS staff successfully developed a system for generating weekly reports for state and national officials during the vaccine shortage, it quickly became clear that such rapid turnaround of data could cause confusion. During the first eight weeks, the generation of reports was so rapid that by the time the reports filtered to the top of the state and federal agencies, new reports were available. At times this caused confusion, as different prevalence estimates were reported by different organizations within the government. It was soon recognized that monitoring changes on a weekly basis was not necessary, and a biweekly schedule was put into place. Again, the emphasis was placed on actionable information, and biweekly updates of vaccine coverage were deemed sufficient to monitor the situation as it occurred and to develop public health messages. Later in the season, monitoring was reduced to a monthly basis. Different situations, however, may call for more (or less) frequent reporting.

Contractual & Financial Issues

Another important consideration is how to channel funding to data collectors to cover the costs of the rapid response surveillance. Although changes in scope are fairly common in most data collection contracts, jumping the required bureaucratic hurdles can be time consuming. When speed is of the essence, these types of constraints can reduce an organization's ability to mount a rapid response effort. Further, multiple layers of authorization may be required. For instance, the BRFSS is set up as a grant from CDC to the states. The states, in turn, often contract with an outside organization for the collection of data. Thus, at a minimum, authorization for a change in scope for the BRFSS requires approvals at the federal, state, and contractor levels. While more centralized data collection systems (that is, when the government agency works directly with a data-collection contractor) may have fewer levels through which to maneuver, maintenance of the contract and the ability to modify the contract still can be time consuming. Ideally, therefore, ongoing surveillance efforts should include clauses in all contracts between the original funding agency and the data collector that allow the rapid expansion of scope and the efficient transfer of funds to where they are needed.

CONCLUSION

Ongoing health surveys can provide nearly real-time information for public health officials during a health emergency. The scope of information required will vary significantly from situation to situation, but large nationwide surveys such as the BRFSS can be modified rather quickly to collect critical data to inform decision making. Moreover, data already collected by these systems can help in preparing for an effective response when crises arise. As an analysis of pre-Katrina New Orleans demonstrated, current health surveys can provide estimates of the potential need for care among those with chronic diseases (such as diabetes, asthma, and cardiovascular disease), health risk behaviors (such as binge drinking and smoking), and infectious diseases (Ford et al., 2006).

Currently missing, however, are assessments of the potential uses and capabilities of current ongoing surveys and established guidelines for rapid response that can be implemented when needed. Protocols are needed for question development and testing, alternative sampling strategies, established data collection procedures for use during health emergencies, automated backend and reporting systems, and flexible contract vehicles for dealing with emerging issues. Such plans can and should be developed for a variety of potential public health crises and should involve input from a variety of sources, including federal, state, and local public health officials; those involved with management and oversight of these survey systems; and the data collectors and processors themselves, who can provide valuable insights on rapid process changes and implementation. Thinking through and solving many of the statistical, operational, and contractual issues beforehand can help ensure the quality and timeliness of critical information when it is needed most to mount an effective response to a public health emergency.

REFERENCES

Centers for Disease Control and Prevention. (2002). Psychological and emotional effects of the September 11 attacks on the World Trade Center—Connecticut, New Jersey, and New York, 2001. *Morbidity and Mortality Weekly Report, 51*(35), 784–786.

Centers for Disease Control and Prevention. (2003). Knowledge, attitudes, and behaviors about West Nile virus—Connecticut, 2002. *Morbidity and Mortality Weekly Report, 52*(37), 886–888.

Centers for Disease Control and Prevention. (2004a). Interim influenza vaccination recommendations, 2004–05 influenza season. *Morbidity and Mortality Weekly Report, 53,* 923–924.

Centers for Disease Control and Prevention. (2004b). Estimated influenza vaccination coverage among adults and children—United States, September 1–November 30, 2004. *Morbidity and Mortality Weekly Report, 53*(49), 1147–1153.

Centers for Disease Control and Prevention. (2005). Estimated influenza vaccination coverage among adults and children—United States, September 1, 2004–January 31, 2005. *Morbidity and Mortality Weekly Report, 54*(12), 304–307.

Ford, E. S., Mokdad, A. H., Link, M. W., Garvin, W. S., McGuire, L. C., Jiles, R. B., et al. (2006). Chronic disease in health emergencies: In the eye of the hurricane. *Preventing Chronic Disease* [serial online], 3(2), A46. Retrieved May 18, 2007, from www.cdc.gov/pcd/issues/2006/apr/05_0235.htm

Groves, R. (2006). Nonresponse rates and nonresponse bias in household surveys. *Public Opinion Quarterly, 70*, 646–675.

Keeter, S., Miller, C., Kohut, A., Groves, R., & Presser, S. (2000). Consequences of reducing nonresponse in a national telephone survey. *Public Opinion Quarterly, 64*, 125–148.

Link, M. W., Ahluwalia, I. B., Euler, G. L., Bridges, C. B., Chu, S. Y., & Wortley, P. M. (2006). Racial and ethnic disparities in influenza vaccination coverage among adults during the 2004–2005 season. *American Journal of Epidemiology, 163*(6), 571–578.

Mokdad, A. H., Stroup, D. F., & Giles, W. H. (2003). Public health surveillance for behavioral risk factors in a changing environment: Recommendations from the Behavioral Risk Factor Surveillance Team. *MMWR Recommendations and Reports, 52*(RR-9), 1–12.

Schmalfeldt, B. (2005, November 1). *President Bush uses NIH stage to launch $7.1 billion bird flu pandemic plan.* National Institutes of Health Radio transcript. Retrieved July 3, 2007, from www.nih.gov/news/radio/nov2005/11012005pandemic.htm

[Note] Corresponding author: Michael W. Link, Centers for Disease Control and Prevention, 4770 Buford Highway NE, Mailstop K-66, Atlanta, GA 30341-3717. Telephone: 770-488-5444. E-mail: MLink@cdc.gov

FEATURE PAPER: Methodological Issues in Post-disaster Mental Health Needs Assessment Research[Note]

Ronald C. Kessler, *Harvard Medical School*
Terence M. Keane, *National Center for PTSD, VA Boston Healthcare System*
Ali Mokdad, *Centers for Disease Control and Prevention*
Robert J. Ursano, *Center for the Study of Traumatic Stress, Uniformed Services University*
Alan M. Zaslavsky, *Harvard Medical School*

Although mental health needs assessment surveys are carried out after many large natural (Ironson et al., 1997; Kohn et al., 2005) and human-made (Gidron, 2002; North et al., 2004) disasters, the paradigm for carrying out these surveys is surprisingly underdeveloped. Many surveys use unrepresentative samples. The optimal timing of surveys has not been established. Substantial differences exist in the measures used across these surveys, limiting the extent to which findings can be generalized. These problems arise in good part because most disaster mental health research is post hoc in the sense that it is planned only after a disaster occurs. Synthesis of findings requires more coordination. Recognizing this fact, the National Institute of Mental Health recently proposed that a Disaster Mental Health Research Center (DMHRC) be created to coordinate survey research on disasters (www.grants.nih.gov/grants/guide/rfa-files/RFA-MH-07-070). Based on our experience in carrying out post-disaster mental health needs assessment surveys, we believe that the major methodological challenges in such an undertaking will involve research design. The current paper reviews the major design challenges that we think this Center will face and make recommendations for addressing these challenges. The paper draws heavily from examples on our recent work carrying out mental health needs assessment surveys among people who lived through Hurricane Katrina (www.HurricaneKatrina.harvard.med.edu).

GENERAL POPULATION SAMPLING

A major challenge in carrying out post-disaster needs assessment surveys is to select a representative sample of all the people exposed to the disaster. This is often quite difficult for logistic reasons, but it is important because surveys based on unrepresentative samples will provide biased information about need for mental health services. A good illustration of the current state of the art can be found in research on the population affected by Hurricane Katrina. There were three major mental health needs assessment surveys carried out soon after Hurricane Katrina, all of which focused on small high-risk populations: the residents of evacuation centers (ECs) (Centers for Disease Control and Prevention [CDC], 2006b), people still living in New Orleans shortly after the hurricane (CDC, 2006a), and evacuee families residing in FEMA-sponsored trailers or hotel rooms in Louisiana as of mid-February (Abramson & Garfield, 2006). These surveys documented substantial psychological distress among respondents, but the public health importance of the three surveys was limited by the fact that each focused on a special population that made up less than 1% of the affected population without including comparison information on other vulnerable population segments or the total population. This made it impossible to know the extent to which the targeted samples were, in fact, those with greatest vulnerability. For example, no comparable surveys were carried out in the much larger segment of the hurricane population in rural Alabama or Mississippi, where entire communities were destroyed and access to services was low. Focusing on selected pockets of vulnerability led to a risk that the surveys might increase health disparities by turning the attention of authorities away from other, possibly larger, segments of the population that might have had even greater need for services.

Why were these three surveys carried out in such small and unrepresentative segments of the population? One reason is presumably that the researchers believed that the people in these segments of the population had especially high risk of mental illness, but, as noted above, this should be a matter documented empirically in general population surveys rather than assumed. Another reason for focusing on these small population segments, though, was almost certainly the fact that each of them was a well-defined high-risk group that could easily be surveyed, while it would have been a much more daunting task to survey the entire population affected by the hurricane. The main difficulty in this regard would have involved sampling, as many of the residents of the area affected by Katrina evacuated after the storm, while damage to roads and telephone lines would have made it very difficult to survey those who remained in the area. Yet such broad-based surveys are necessary in order to assess the magnitude of unmet need for treatment of post-disaster mental disorders.

The difficulties associated with selecting a representative sample of disaster survivors differ depending on whether the disaster is geographically defined. In the case of natural disasters (e.g., tornados, hurricanes) or human-made disasters that have a geographic epicenter (e.g., the Oklahoma City bombing), area probability household sampling is feasible. There are inevitable practical problems with this form of sampling that can be exacerbated by mass evacuation. As described below, though, multiple-frame sampling (Skinner & Rao, 1996) can be used to decrease coverage problems in situations of this sort. In the case of disasters that do not have a geographic epicenter (e.g., a plane crash), in comparison, the use of list samples is a necessity, unless the researchers have the resources to engage in large-scale mass screening, using multiplicity sampling (Kalton & Anderson, 1986) whenever possible to increase the efficiency of the screening exercise. In any of these cases, frame biases have to be taken into consideration. In particular, landline telephone frames might underrepresent the most disadvantaged segments of the population (Brick, Dipko, Presser, Tucker, & Yuan, 2006), making it particularly useful to implement a multiple-frame sampling approach (see below) that enriches the less restrictive frame for high-risk cases, possibly by oversampling census blocks with low rates of landline telephone penetration or high rates of poverty

Both approaches will be needed in mixed cases, as in the 2005 train crash in Graniteville, South Carolina, that released toxic chemicals into the local environment, leading to injury, death, and toxic exposure among the passengers and crew of the train and to risk of toxic exposure, evacuation, and community disruption among residents of the community in which the crash occurred (U.S. Environmental Protection Agency, 2005). In a situation of this sort, the residents of the community are geographically clustered, while the surviving passengers and crew of the train are not.

USING A MULTIPLE-FRAME SAMPLE DESIGN TO ADDRESS SAMPLING PROBLEMS

We faced an especially complex situation with regard to sampling in assembling the Hurricane Katrina Community Advisory Group (CAG), a representative sample of all pre-hurricane residents of the areas affected by Katrina. A small proportion of the population, presumably representing the most high-risk pre-hurricane residents of the areas most hard hit by the storm and resulting flood in New Orleans, were living in evacuation centers (ECs) and, later, FEMA-sponsored hotel rooms, trailers, and even luxury liners. Many other pre-hurricane residents of the New Orleans metropolitan area were scattered throughout the country, largely living with relatives, but also in communities that had established evacuation centers and subsequently created community living situations in which a certain number of needy families from New Orleans were, in effect, adopted by the community. The vast majority of pre-hurricane residents of the other hurricane-affected areas in Alabama, Louisiana, and Mississippi remained living either in their pre-hurricane households or in the surrounding community in which they lived before the hurricane as they went about repairing the damage to their homes and communities. Telephone lines were down in many parts of the affected areas for a considerably longer time than is typical in U.S. natural disasters. In addition, physical movement was made difficult by infrastructure damage and difficulty finding gasoline. Conventional household enumeration was further made difficult by the fact that many pre-hurricane homes no longer existed.

At the same time, we had several important resources available to us that we used in building a multiple-frame sampling strategy that combined information from a number of restricted frames to assemble the sample of people who participated in the CAG. In particular, the American Red Cross (ARC) and the Federal Emergency Management Agency (FEMA) both had extensive lists of people who registered for assistance. We were fortunate to have access to these lists. In addition, over 400,000 hurricane survivors posted contact information on one or more “safe lists” set up on the Web by CNN, MSNBC, the ARC, and others. Another rather unexpected resource was the use of random-digit-dialing (RDD). It seems counterintuitive that RDD could be used to study Katrina survivors in light of the fact that the vast majority of the New Orleans population was forced to evacuate their homes after the storm and the fact that many people who lived in other areas affected by the hurricane had nonworking landlines because of damage to the telephone infrastructure. However, the main telephone provider in the hurricane area forwarded phone calls into the hurricane area to new numbers (either landline or cell phone numbers) outside the area that were registered by the owners of the pre-hurricane numbers. As a result of this service, we were able to call an RDD sample of pre-hurricane phone numbers in New Orleans and connect with many displaced pre-hurricane New Orleans residents in temporary residences all across the country.

We used all these frames to create a multiple-frame sample. To reduce overlap with the RDD frame, we restricted our use of the ARC and FEMA lists to cell phone exchanges and to landline exchanges in areas outside of the RDD sampling area. Over 1.4 million families representing more than 2.3 million adults applied to the ARC for assistance and provided post-hurricane contact information that included new residential addresses, telephone numbers (often cell phones), and e-mail addresses. An even larger number of families (roughly 2.4 million) applied to FEMA for assistance and also provided post-hurricane contact information comparable to the ARC list information. As one would predict, considerable overlap existed in the entries on these two lists, but the more surprising finding was that a substantial number of families applied only to one of the two. There were also a number of families that fraudulently applied on multiple occasions and at different locations to the same agency. We corrected for these multiple counts in sampling from these lists by differential weighting of cases depending on their appearance in one or both lists.

By the time the baseline CAG survey was fielded, all the Katrina evacuation centers had been closed and only a small number of evacuees were still housed in FEMA-supported hotel rooms. This made it relatively easy to screen a representative sample of hotels selected from a commercial sampling frame to find hotels housing evacuees, to use information provided by hotel managers to select a sample of rooms with probabilities proportional to size from these hotels, and to include the respondents interviewed in this way as a supplemental sample. Not surprisingly, though, this exercise showed that virtually all hotel evacuees were included with valid contact information on the FEMA relief list that we were using as one of the main sample frames. As with respondents sampled from each of the other frames, information was included about this overlap and used in making weighting adjustments in the consolidated CAG sample.

The availability of these different frames allowed us to use relatively inexpensive telephone administration to reach the great majority of people who were living in the areas affected by

Katrina before the hurricane. As noted above, we reduced overlap between the two main frames by restricting our use of the ARC and FEMA lists to cell phone exchanges and to landline exchanges in areas outside of the RDD sampling area. In addition, we collected data from every respondent in the entire sample that allowed us to determine whether they had a nonzero probability of selection in each frame. For example, we asked respondents in the RDD sample if they applied to the ARC and to FEMA for assistance. This information made it possible for us to use conventional weighting procedures for overlapping sample frames (Fisher, Turner, Pugh, & Taylor, 1994) to estimate the size of each population segment defined by the multivariate profiles of their existence or nonexistence in each frame, and to use these estimates of size to develop weights that were used to combine these segments into an equal-probability sample of the population.

Concerns could be raised about under-representing evacuees who lived outside the hurricane area not on either the ARC or FEMA lists, as well as residents of the affected area who remained in the area but could not be contacted by telephone. We attempted to reach the first of these two groups with a national RDD sample that employed multiplicity methods (i.e., asking for evacuees among current household residents and among first-degree relatives of a randomly selected informant in each household) either with live telephone interviewers or interactive voice response (IVR) messages with follow-up live telephone interviewers. We screened a nationally representative sample of 20,000 listed telephone numbers and found a hit rate of only about one in 1,000. However, virtually all of these evacuees had applied either to the ARC or to FEMA for assistance with traceable contact information, which means that the national RDD did not pick up new cases—these people were already part of our primary sample frames, making it unnecessary to screen for them in a supplemental national RDD sample.

The most feasible way to reach the remaining groups that are underrepresented in the frames discussed above (i.e., evacuees who could not be reached by phone) using probability sampling would have been to use a survey field staff to carry out face-to-face interviews. This could be done most efficiently by adding a screening question for evacuees in the major ongoing face-to-face government surveys—the NHIS and the NSDUH—and going back to the evacuees detected in this way for separate interviews. We did not do this in our survey of Katrina survivors due to financial constraints and lack of time to work out appropriate collaborations to allow screening questions to be included on the NHIS and NSDUH. It would be very useful, though, if an arrangement for this kind of screening was worked out in advance to prepare for the inevitability of a major disaster in the future that, like Katrina, leads to mass evacuation. The NHIS and NSDUH would screen only households, of course, so additional plans would need to be made to screen remote evacuation centers and other group quarters that house disaster evacuees.

Based on these experiences, the most feasible approach to multiple-frame sampling in future disasters would probably be to begin with a Metro Mail list of all mail addresses in the affected area and to map information from more restrictive sample frames into this master list prior to sampling. Sampling then could be based on this master list, possibly oversampling subareas known to be most seriously affected by the disaster and the households of people who sought disaster assistance. It is important to recognize that ancillary lists could be used whenever possible, such as lists of subscribers to medical care organizations (MCO) who might have called the 800 number of the MCO to obtain authorization for treatment in a different city or state in the wake of the disaster and provided tracing information. Multimode data collection would be used in these surveys, with telephone interviews being attempted in a representative sample of households with known pre-disaster phone numbers and face-to-face interviews being attempted in households without telephones, in telephone households where numbers are not working, and in samples of the non-household population (e.g., people living in disaster evacuation centers).

HIGH-RISK POPULATION SAMPLING

Certain high-risk groups are highly exposed to disaster stressors (e.g., evacuees who lost their homes and are housed in group evacuation centers), have unique vulnerabilities or risk factors (e.g., disaster survivors with a history of serious mental illness before the disaster), or are critical to community function immediately post-disaster (e.g., first responders) as well as for long-term recovery (e.g., emergency medical personnel) (Ben-Ezra, Essar, & Saar, 2006; Fullerton, Ursano, & Wang, 2004). Although they often make up only a small percentage of all the people affected by a disaster, such high-risk groups are important to study because they may contain a large proportion of the people most severely affected by disasters. High-risk groups vary widely across disaster situations. The workers in a government office building that was the target of an anthrax attack along with their families may be a high-risk group in one disaster situation, while the residents of a geographic area close to a toxic chemical spill might be a high-risk group in another disaster situation. In the case of natural disasters, there are also expectable high-risk groups, such as residents of nursing homes and people with physical disabilities who would have a difficult time evacuating. It is useful to consider ways to enrich general population samples to include a large enough sample of these high-risk people to allow separate analysis of their special needs.

In the case of comparatively rare high-risk groups, the only practical option for oversampling is to gain access to a list sample that can be used as a sampling frame for tracing. Lists should be available on first responders, and local health plans might have lists of people who were in treatment for serious mental disorders prior to the disaster so that this especially vulnerable group could be traced to determine the extent to which they are affected by the disaster. In the special case where evacuation is an issue, pre-hurricane residents of nursing homes represent a high-risk group of special interest. Given that nursing homes have to be licensed, it should be possible to create a list of all such facilities that could be used as an ancillarysampling frame. In addition, it sometimes might be possible to merge multiple list samples to refine sampling or answer certain critical policy questions regarding high-risk populations. For example, a comprehensive list of all nursing home residents in a disaster area could be linked to the National Death Index (NDI) to address concerns that the relocation was associated with a substantial increase in mortality of nursing home residents. Linkage of this sort can be done across multiple administrative data systems to generate very useful data, especially when done in conjunction with follow-up surveys. It would be possible, for example, to use linked income tax records and mortality records to track the mortality experience of pre-disaster residents of the affected areas who either subsequently returned to their pre-disaster residence or moved to a different part of the country.

PANEL VS. TREND STUDY DESIGNS TO MONITOR CHANGE

Both panel designs and trend designs can be used to monitor health and behavioral change in populations. The panel design is preferable to the trend design when the main purpose of tracking is to use baseline information about risk to predict the subsequent onset of some adverse outcome that might be the subject of preventive intervention. For example, there is considerable interest in the literature on posttraumatic stress disorder (PTSD) in the extent to which baseline information obtained shortly after a disaster (the "peritraumatic" time period) can identify disaster victims at risk of subsequently developing PTSD (e.g., Shalev & Freedman, 2005; Simeon, Greenberg, Nelson, Schmeidler, & Hollander, 2005). Panel data are needed to investigate such individual differences. However, the panel design is inferior to the trend design when the purpose of the study is to monitor aggregate trends, as the problems of sample reactivity and attrition cumulate in a panel design but not in a trend design.

While the ideal is to combine the panel and trend designs in a single coordinated study, it is sometimes necessary for practical reasons to choose one. That was the situation with our needs assessment surveys of Katrina victims, where we used a panel design even though we were interested, as least in part, in studying aggregate trends. The decision not to include a trend component was based on the high costs and complexity of selecting the baseline sample. We didn't have enough funds to select a new sample each time we carried out a subsequent wave of data collection. But this raises the concern about problems of tracking the movements of respondents and of respondent burnout. The only way to assess the magnitude of these problems is to carry out a trend survey in parallel with the panel survey to see the extent to which aggregate estimates differ in the two samples. Some version of a mixed panel-trend design usually would be the preferred design when the complexities of sampling are not so great that this approach is prohibitively expensive.

SAMPLING TIME

The time interval is an important design consideration in longitudinal tracking studies. This is especially true when the goal of a study is to track trends in order to monitor and evaluate the effects of interventions on an ongoing basis and to use such results to guide modificationsin the interventions. Some tracking surveys of this sort are carried out every week or every month, in which case respondents typically are asked to report their experiences over the past week or month. Other tracking surveys are carried out for different purposes in which trends are tracked at wider time intervals (e.g., every six months) and respondents are asked to report their experiences over a much longer recall period. Others are carried out over a wide time interval (e.g., a new survey every six months), and respondents are asked to report their experiences over a shorter recall period (e.g., the past week or past month). The first two of these designs are examples of continuous-time tracking designs, in which the researcher attempts to capture information across the entire interval since the disaster. In comparison, the third design (i.e., six-month intervals between data collection waves with past-week recall questions) is an example of a "snapshot" design, in which the researcher attempts to collect data only in a sample of time intervals rather than to capture information about experiences over the entire interval since the disaster.

The decision between the continuous-time design and the snapshot design depends on a number of substantive and logistical considerations that can vary from one study to the next. The most commonly used design in post-disaster needs assessment surveys is a mixed design in which the time interval between waves of data collection is fairly long (6–12 months), some information is collected in a continuous-time framework (e.g., retrospective questions about the persistence of PTSD over the entire time interval since the last survey), while other information is collected in a snapshot framework (e.g., questions about current needs for services). However, this is unlikely to be the optimal design for addressing the research questions these studies typically are designed to address. The mixed design is the right one, as needs assessment surveys always have multiple goals and it is important to build in the flexibility to include questions that focus on diverse time intervals. However, the long time intervals that typically exist between waves are suboptimal, as they make it likely that recall bias will be magnified and that potentially important short-term trends will be missed.

Based on these considerations, a strong argument could be made for a continuous tracking design using the mixed panel-trend approach as described in the last subsection. A variety of mixed panel-trend designs exist (Kish, 1987). One of the most appealing is the rolling panel design, in which new trend survey respondents are recruited on a regular basis (e.g., in monthly samples) and followed over a specified series of panel waves that overlap in time with new trend surveys. This is the design used, for example, in the ongoing Bureau of Justice Statistics National Crime Victimization Survey. Random effects regression analysis can be used to estimate the impact of nonresponse bias in the panel component of the data on estimates of trends by taking into consideration systematic variation in trend estimates across the subsamples (Verbeke & Molenberghs, 2001).

Given that the tracking period for post-disaster needs assessment surveys is typically rather short (no more than several years), a useful variant on the rolling panel design is to begin with a rather large baseline sample interviewed as soon as possible after the disaster to assess early peritraumatic stress reactions and obtain rapid response information about need that can be provided quickly to service planners. In addition, smaller trend samples could be selected on a weekly or monthly basis over the time period in which recovery is being tracked to provide fine-grained information on aggregate trends in persistence or remission of symptoms. Fine-grained tracking could be especially useful when carried out in conjunction with monitoring of mass media messages and treatment recruitment efforts in order to provide information about the effects of public education and social marketing interventions on knowledge, attitudes, and behavior.

Respondents in the baseline interviews could then be re-interviewed after some conceptually specified time interval in a panel design. The panel component could be carried out with the full baseline sample in a rolling panel framework (e.g., respondents initially interviewed in month 1 re-interviewed in month 7, those initially interviewed in month 2 re-interviewed in month 8, etc.) so as to have continuous information being collected each month, possibly including a small trend component (e.g., a small representative sample of new respondents interviewed each month in months 7+). Or the panel interviews could be carried out with a probability subsample of baseline respondents that oversamples those with baseline indicators of long-term risk (e.g., retrospectively reported pre-disaster history of psychopathology, extreme peritraumatic stress reactions, high exposure to disaster-related stressors).

Mixed panel-trend designs such as those described in the last paragraph lead to maximum flexibility in addressing a wide range of substantive issues and allow for rapid assessment of population response to mini-interventions (e.g., an announcement that special funds have been allocated by the federal government for disaster relief, an announcement that ERA tests documented that fears of toxic chemical exposure were unfounded). This can be accomplished both through the investigation of time series in point prevalence of mental disorders and through the inclusion of new public opinion questions on weekly or monthly waves of the survey that ask explicitly about awareness of and reactions to the mini-interventions.

It is important to recognize that the notion of “continuous” time sampling is a misnomer, as retrospection is always needed in longitudinal data collection, even when the interval between waves is very short. Recall bias can easily creep into retrospective reports, especially in reports of emotional experiences. Indeed, methodological research has shown that bias can be found in emotion reports even over a recall period as short as 24 hours (Diener & Seligman, 2004). Researchers interested in reducing this bias have developed the method of Ecological Momentary Assessment (ESA) (Stone, Shiffman, & deVries, 1999). ESA uses beepers programmed to go off at random times in the day and diaries for respondents to record moment-in-time feelings across a sample of moments and days. An ESA trend study might recruit a separate random sample of disaster victims each week for one year and ask them to complete moment-in-time assessments at five randomly selected moments on each of the seven days of the week. ESA assessment can be very useful adjuncts to more conventional panel data collection (e.g., deVries, 1987; Wang et al., 2004). When ESA is considered too molecular, a daily diary can be used instead. In this case, respondents are asked to record the experiences of their day before they go to bed each evening over the course of a one- or two-week diary period (e.g., Chepenik et al., 2006; Henker, Whalen, Jamner, & Delfino, 2002).

BEFORE-AFTER DESIGNS

An important limitation of virtually all disaster needs assessment surveys is that respondents are interviewed only *after* the disaster, making it impossible to make direct before-after comparisons that could estimate the impact of the disaster on the prevalence of mental disorders in the population. It is noteworthy in this regard that the sociodemographic correlates of mental disorders in post-disaster surveys are very similar to those in general population epidemiological surveys (Brewin, Andrews, & Valentine, 2000; Galea, Nandi, & Vlahov, 2005), raising the possibility that the mental health effects of some disasters may be more to magnify pre-existing disorders than to cause new disorders. We examined this issue in our work with those who lived through Katrina by comparing prevalence estimates of our mental health outcomes in the CAG sample with the same outcomes assessed in an earlier survey of 826 adults in the census divisions later affected by Hurricane Katrina (Kessler, Galea, Jones, & Parker, 2006). The significant sociodemographic predictors of the outcomes did not differ significantly in the two samples, suggesting that the increases in mental illness found after the hurricane compared to before were unrelated to major sociodemographic variables despite these variables being related to point-in-time measures of mental illness after the hurricane.

A practical approach to introduce before-after information into virtually any disaster survey carried out in the U.S. is to use tracking information from ongoing government health surveys to construct an appropriate post hoc pre-disaster comparison group or to create a follow-back panel sample selected from the respondents who participated in the year before the disaster in a government survey. The BRFSS, NHIS, and NSDUH all could be used in this way. Importantly, all three of these surveys include a version of the K-6 psychological distress scale (Kessler et al., 2002; 2003), a global screening measure of DSM-IV anxiety-mood disorders that could be used to study pre-post differences in mental illness in disaster populations.

Of course, a question exists whether these surveys have a large enough number of pre-disaster respondents in any one area to support pre-post analysis. They do. Consider, for example, the case of Oklahoma City (3,450,000 residents in the 2000 Census), the site of a 1995 bombing of a U.S. government office complex that killed 168 people. Given the size of the three surveys described above and the size of Oklahoma City, it is likely that a sample of roughly 5,000 adult residents of Oklahoma City would have been interviewed in one of these surveys in the 12 months before the terrorist attack if all three surveys had been in place in the mid-1990s. A sample as large as this would create a very stable baseline for assessing the mental health effects of the terrorist attack. In the case of smaller disaster areas, it would be possible to combine information from similar communities collected over the prior 12 months to construct an approximate pre-disaster comparison group. Or data could be combined from interviews with residents of areas in the vicinity of the disaster site collected over a decade or more before the disaster with post-disaster interviews in the affected area and use interrupted time series analysis (McDowell, McCleary, Meidinger, & Hays, 1980) to estimate the effect of the disaster on the mental health of residents.

There are bureaucratic impediments to carrying out this type of analysis, in that the government agencies that administer the three ongoing surveys have restrictions on making information available to researchers about small area geographic characteristics of individual respondents. This is part of a much larger problem of coordination that occurs across agencies involved in disaster situations (Mokdad et al., 2005). An especially important component of this problem is that statistical agencies are often slow in releasing the survey data for public use, making it impossible to obtain pre-disaster data in a timeframe that would be useful for disaster response planning purposes. These impediments made it impossible for us to use data from any of these surveys in pre-post analyses of the mental health effects of Hurricane Katrina even though we estimate that more than 6,000 residents of the areas affected by Katrina were respondents in one of these three surveys in the 12 months before the hurricane. Efforts have been made recently, though, to decrease the time delays in producing usable data files from these surveys.

SURVEYING HELP-SEEKERS

Help-seekers presumably differ from other residents of disaster populations in a number of ways, including both in the extent of their need for help (e.g., the extent to which they experienced property loss in the disaster) and in the extent to which they are motivated and capable of making an application. Although we might expect to find a meaningful number of victims with high need who did not seek help due to extreme physical restrictions (e.g., housebound in a wheelchair), possibly in conjunction with extreme social isolation and communications problems (e.g., no access to a telephone, unable to speak English, blind or deaf), relief agencies make efforts to find such people through a variety of community outreach and household screening programs. Based on this fact, it is not unreasonable to think that fairly representative data on demand for services could be obtained by sampling people who applied for relief even though the sample might not represent all people with need for services.

A very important group of post-disaster help-seekers for treatment of mental disorders is those who call mental health crisis hotlines established by local and national mental health associations. The largest and most important of these is the National Suicide Prevention Lifeline, the only national suicide prevention and intervention telephone line sponsored by the federal government (www.suicidepreventionlifeline.org). It was launched in December 2004 to link callers to staff in more than 120 mental health crisis centers around the country. (SAMHSA used the Lifeline crisis phone number as the hub for mental health referrals during Katrina's aftermath and is likely to do so again in future mass disasters.)

Follow-up needs assessment surveys with callers of the Lifeline and other crisis hotlines could be useful components of larger post-disaster mental health needs assessment efforts in at least three important ways. First, unmet need for treatment of mental health problems after disasters is an understudied issue (Boscarino, Adams, Stuber, & Galea, 2005; Stuber & Galea, 2005). A useful way to study this issue would be to carry out follow-up interviews with callers of mental health hotlines who were given a referral for treatment. The information obtained in these interviews about modifiable barriers to treatment could be organized using existing conceptual frameworks (Rogler & Cortes, 1993) to provide insights into potential value modifications in the referral process. We know of no previous research of this sort carried out with callers to post-disaster mental health referral lines. For this reason, we have established collaborations with the ARC and with Mental Health America (MHA; formerly known as the National Mental Health Association) as well as with a number of MHA affiliates, including the National Suicide Prevention Lifeline, to implement this type of study as part of possible future post-disaster needs assessment tracking surveys.

Second, relatively little is known about the quality of care provided to patients referred by crisis hotlines after disasters to local mental health treatment centers. This quality control problem could be addressed, at least in part, by carrying out systematic follow-up interviews that assess patient satisfaction. Surveys of this sort are now a routine part of many treatment quality assurance programs, the most notable example being the Consumer Assessment of Healthcare Providers and Systems (CAHPS) program (www.cahps.ahrq.gov), which now includes a behavioral health care component. Publicizing the “report cards” generated by the results of these surveys in conjunction with other quality indicators has been shown to influence consumer choice of health plans (Jin & Sorensen, 2006; Oetjen, Fottler, Unruh, & Rehman, 2006), which, in turn, is hoped to influence health plan performance. As part of the proposed collaboration with MHA noted in the last paragraph, we plan to develop a similar system that will carry out CAHPS-like follow-up surveys with patients referred to post-disaster mental health services. It is important for these surveys to be very inexpensive because the goal would be to give all patients a chance to respond so as to obtain countable information for as many service providers as possible. As a result, patients who have an e-mail address will be surveyed using inexpensive Web survey technology (Schonlau, Fricker, & Elliott, 2002), while other patients will be interviewed using inexpensive IVR technology.

Third, there is considerable uncertainty about the most appropriate interventions to use in treating the emotional problems of disaster victims (Watson & Shalev, 2005). This uncertainty is due in no small part to the difficulties involved in carrying out controlled treatment studies in disaster situations. A potentially useful way to address this problem would be to build in randomization of referrals of help-seekers to different treatment settings and types in conjunction with the follow-up interviews described in the last two paragraphs. This approach could be used to evaluate a highly specified treatment approach that is experimentally provided to a small probability subsample of help-seekers in comparison to the usual care provided to all other disaster victims. Alternatively, all help-seekers could be randomized across the range of seemingly appropriate treatment settings available in a given disaster situation and follow-up questionnaires of the sort described in the last paragraph could be used to determine whether effectiveness varies significantly across these settings, both in the aggregate and for patients with particular characteristics. With regard to the latter, the large numbers of patients included in the randomization in a major disaster would make it possible to determine whether overall treatment effectiveness could be improved by some type of patient-program matching.

OVERVIEW

The design recommendations made here have the potential to be very important in light of several facts. First, natural and human-made disasters are quite common occurrences in the U.S. and are likely to increase in frequency in the future. Both weather-related natural disasters (hurricanes, tornadoes) and hydrometeorological disasters (floods, earthquakes) have increased in prevalence over the past few decades and are likely to continue to do so in the coming years due to population growth and environmental degradation (International Federation of Red Cross and Red Crescent Societies, 2006). Accident-related disasters (e.g., airplane crashes, toxic chemical spills, nuclear accidents) also are likely to increase with the increase in the technological complexity of society (Krey, 2006). Second, disasters have substantial effects on the mental health of those exposed to them, while only a minority of people with clinically significant disaster-related mental disorders receive adequate treatment (Canino, Bravo, Rubio-Stipec, & Woodbury, 1990; Madakasira & O'Brien, 1987). Third, mental health needs assessment research currently does not take advantage of the opportunities for enhancement described in this paper. These recommended enhancements have the potential to provide much more useful and timely information about unmet need for treatment and barriers to treatment of post-disaster mental disorders than currently exists.

REFERENCES

Abramson, D., & Garfield, R. (2006). *On the edge: Children and families displaced by Hurricanes Katrina and Rita face a looming medical and mental health crisis.* Columbia University Mailman School of Public Health.

Ben-Ezra, M., Essar, N., & Saar, R. (2006). Gender differences and acute stress reactions among rescue personnel 36 to 48 hours after exposure to traumatic event. *Traumatology, 12,* 139–142.

Boscarino, J. A., Adams, R. E., Stuber, J., & Galea, S. (2005). Disparities in mental health treatment following the World Trade Center Disaster: Implications for mental health care and health services research. *Journal of Traumatic Stress, 18,* 287–297.

Brewin, C. R., Andrews, B., & Valentine, J. D. (2000). Meta-analysis of risk factors for posttraumatic stress disorder in trauma-exposed adults. *Journal of Consulting and Clinical Psychology, 68,* 748–766.

Brick, M. J., Dipko, S., Presser, S., Tucker, C., & Yuan, Y. (2006). Nonresponse bias in a dual frame sample of cell and landline numbers. *Public Opinion Quarterly, 70,* 780–793.

Canino, G. J., Bravo, M., Rubio-Stipec, M., & Woodbury, M. (1990). The impact of disaster on mental health: Prospective and retrospective analyses. *International Journal of Mental Health, 19,* 51–69.

Centers for Disease Control and Prevention. (2006a). Assessment of health-related needs after Hurricanes Katrina and Rita—Orleans and Jefferson Parishes, New Orleans area, Louisiana, October 17–22, 2005. *Morbidity and Mortality Weekly Report, 55,* 38–41.

Centers for Disease Control and Prevention. (2006b). Surveillance in hurricane evacuation centers—Louisiana, September–October 2005. *Morbidity and Mortality Weekly Report, 55,* 32–35.

Chepenik, L. G., Have, T. T., Oslin, D., Datto, C., Zubritsky, C., & Katz, I. R. (2006). A daily diary study of late-life depression. *American Journal of Geriatric Psychiatry, 14,* 270–279.

deVries, M. W. (1987). Investigating mental disorders in their natural settings. *Journal of Nervous and Mental Disease, 175,* 509–513.

Diener, E., & Seligman, M. E. P. (2004). Beyond money: Toward an economy of well-being. *Psychological Science in the Public Interest, 5,* 1–31.

Fisher, N., Turner, S. W., Pugh, R., & Taylor, C. (1994). Estimating numbers of homeless and homeless mentally ill people in north east Westminster by using capture-recapture analysis. *British Medical Journal, 308,* 27–30.

Fullerton, C. S., Ursano, R. J., & Wang, L. (2004). Acute stress disorder, posttraumatic stress disorder, and depression in disaster or rescue workers. *American Journal of Psychiatry, 161,* 1370–1376.

Galea, S., Nandi, A., & Vlahov, D. (2005). The epidemiology of post-traumatic stress disorder after disasters. *Epidemiologic Reviews, 27*, 78–91.

Gidron, Y. (2002). Posttraumatic stress disorder after terrorist attacks: A review. *Journal of Nervous and Mental Disease, 190,* 118–121.

Henker, B., Whalen, C. K., Jamner, L. D., & Delfino, R. J. (2002). Anxiety, affect, and activity in teenagers: Monitoring daily life with electronic diaries. *Journal of the American Academy of Child and Adolescent Psychiatry, 41,* 660–670.

International Federation of Red Cross and Red Crescent Societies. (2006). *World disasters report: Focus on neglected crises*. Bloomfield, CT: Kumarian Press.

Ironson, G., Wynings, C., Schneiderman, N., Baum, A., Rodriguez, M., Greenwood, D., et al. (1997). Posttraumatic stress symptoms, intrusive thoughts, loss, and immune function after Hurricane Andrew. *Psychosomatic Medicine, 59,* 128–141.

Jin, G. Z., & Sorensen, A. T. (2006). Information and consumer choice: The value of publicized health plan ratings. *Journal of Health Economics, 25,* 248–275.

Kalton, G., & Anderson, D. (1986). Sampling rare populations. *Journal of the Royal Statistical Society, Series A, 149*, 65–82.

Kessler, R. C., Andrews, G., Colpe, L. J., Hiripi, E., Mroczek, D. K., Normand, S. L., et al. (2002). Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychological Medicine, 32*, 959–976.

Kessler, R. C., Barker, P. R., Colpe, L. J., Epstein, J. F., Gfroerer, J. C., Hiripi, E., et al. (2003). Screening for serious mental illness in the general population. *Archives of General Psychiatry, 60,* 184–189.

Kessler, R. C., Galea, S., Jones, R. T., & Parker, H. A. (2006). Mental illness and suicidality after Hurricane Katrina. *Bulletin of the World Health Organization, 84,* 930–939.

Kish, L. (1987). *Statistical design for research*. New York: John Wiley & Sons.

Kohn, R., Levav, I., de Almeida, J. M., Vicente, B., Andrade, L., Caraveo-Anduaga, J. J., et al. (2005). [Mental disorders in Latin America and the Caribbean: A public health priority]. *Revista Panamericana de Salud Pública, 18,* 229–240.

Krey, N. C. (2006). *Accident trends and factors for 2005*. Frederick, MD: AOPA Air Safety Foundation.

Madakasira, S., & O'Brien, K. F. (1987). Acute posttraumatic stress disorder in victims of a natural disaster. *Journal of Nervous and Mental Disease, 175,* 286–290.

McDowell, D., McCleary, R., Meidinger, E. E., & Hays, R. A. (1980). *Interrupted time series analysis*. Beverly Hills, CA: Sage.

Mokdad, A. H., Mensah, G. A., Posner, S. F., Reed, E., Simoes, E. J., Engelgau, M. M., et al. (2005, November). When chronic conditions become acute: Prevention and control of chronic diseases and adverse health outcomes during natural disasters. *Preventing Chronic Disease* [serial online], *2* (Special issue). Retrieved August 9, 2007, from www.cdc.gov/pcd/issues/2005/nov/05_0201.htm

North, C. S., Pfefferbaum, B., Tivis, L., Kawasaki, A., Reddy, C., & Spitznagel, E. L. (2004). The course of posttraumatic stress disorder in a follow-up study of survivors of the Oklahoma City bombing. *Annals of Clinical Psychiatry, 16,* 209–215.

Oetjen, D., Fottler, M. D., Unruh, L. Y., & Rehman, Z. (2006). Consumer determinants of the use of health plan information in plan selection. *Health Services Management Research, 19,* 232–250.

Rogler, L. H., & Cortes, D. E. (1993). Help-seeking pathways: A unifying concept in mental health care. *American Journal of Psychiatry, 150,* 554–561.

Schonlau, M., Fricker, R., & Elliott, M. (2002). *Conducting research surveys via email and the Web*. Santa Monica, CA: RAND.

Shalev, A. Y., & Freedman, S. (2005). PTSD following terrorist attacks: A prospective evaluation. *American Journal of Psychiatry, 162,* 1188–1191.

Simeon, D., Greenberg, J., Nelson, D., Schmeidler, J., & Hollander, E. (2005). Dissociation and posttraumatic stress 1 year after the World Trade Center disaster: Follow-up of a longitudinal survey. *Journal of Clinical Psychiatry, 66,* 231–237.

Skinner, C., & Rao, J. N. K. (1996). Estimation in dual frame surveys with complex designs. *Journal of the American Statistical Association, 91,* 349–356.

Stone, A. A., Shiffman, S. S., & deVries, M. W. (1999). Ecological momentary assessment. In E. Diener, N. Schwarz, & D. Kahneman (Eds.), *Well-being: The foundation of hedonic psychology*. New York: Russell Sage Foundation.

Stuber, J. P., & Galea, S. (2005). Barriers to mental health treatment after disasters. *Psychiatric Services, 56,* 1157–1158.

U.S. Environmental Protection Agency. (2005). *Norfolk Southern Graniteville derailment: Final information update as of January 21, 2005.* Atlanta: Department of Health and Human Services, Public Health Service, Agency for Toxic Substances and Disease Registry, Division of Health Assessment and Consultation.

Verbeke, G., & Molenberghs, G. (2001). *Linear mixed models for longitudinal data*. New York: Springer-Verlag.

Wang, P. S., Beck, A. L., Berglund, P., McKenas, D. K., Pronk, N. P., Simon, G. E., et al. (2004). Effects of major depression on moment-in-time work performance. *American Journal of Psychiatry, 161,* 1885–1891.

Watson, P. J., & Shalev, A. Y. (2005). Assessment and treatment of adult acute responses to traumatic stress following mass traumatic events. *CNS Spectrums, 10,* 123–131.

[Note] Direct comments to R. C. Kessler, Department of Health Care Policy, Harvard Medical School, 180 Longwood Avenue, Boston MA 02115; Kessler@hcp.med.harvard.edu

SESSION 1 SUMMARY

Kathleen S. O'Connor, *National Center for Health Statistics*
Michael P. Battaglia, *Abt Associates Inc.*

INTRODUCTION

The Session 1 presentations illustrated quite clearly that disasters and other disruptive forces do not adhere to survey timetables or standard survey procedures. Thoughtful consideration of the challenges related to disasters resulted in a lengthy and enthusiastic discussion. The following general themes were discussed during the session:

- constructing sampling frames of persons, households, or establishments affected by an emergency or disaster;
- sampling from registries or lists, oversampling, and the use of alternative strategies, such as random-digit-dial (RDD) telephone samples;
- constructing data collection instruments or question batteries while simultaneously addressing both cognitive and technical aspects;
- implementing single or multiple modes of data collection or changing the mode of data collection "midstream"; and
- estimating, analyzing, interpreting, and disseminating results, while ensuring accurate and responsible use of hastily collected data.

CROSSCUTTING THEMES

Several crosscutting themes emerged from the presentations and discussion period and are detailed below.

Absolute Importance of Advance Preparedness Planning for Each Survey Mechanism

An intriguing suggestion was for survey researchers to develop disaster-specific "modules" or a brief battery of key questions that could be pretested and appropriately approved *before* a disruption. These modules could be integrated into existing data collection to provide baseline data, then efficiently altered and administered post-disaster. In theory, this "pre-event module development" suggestion seems quite plausible. Additionally, it is important to determine how to engage public health decision makers before an event to plan and develop effective systems, especially in a time of fiscal austerity. In particular, how can we effectively engage federal, state, and local officials to develop “best practices” for pre-planning, implementation during a disaster, and post-disaster evaluations?

Disaster Classification

A disaster classification scheme would be very useful to identify distinctive features of a disaster or disruptive event. If such a matrix could be developed by event type, it might allow methodologists to determine scenario-specific, appropriate, and timely responses. A nonexhaustive list of classification characteristics includes (1) infrastructure status (e.g., the mere existence of establishments, households, landline and cellular telephone networks, roads, electricity, computer networks, or refrigeration facilities [if specimen(s) need to be collected]), (2) the coverage, depth, and type(s) of destruction; (3) defining characteristics of the event type (e.g., natural disaster versus man-made events [terrorist attack(s)]) and resulting mediation or control strategies (e.g., imposition of mandatory quarantine strategies in the event of pandemic flu or SARS); and (4) the potential random (or nonrandom) dispersion patterns of the affected population(s) after an event, as well as immediate and long-term methods to recontact and track these respondents. We also should broaden our thinking and learn more about the stochastic and nonstochastic elements per disaster type (such as developing predictive theories for natural and manmade events, learning about the genesis and movement of hurricanes, etc.). As part of the classification system, advance consideration also must be given to determining and sustaining a clear accountable chain of command and appropriate timetable for key tasks when disasters occur. A key question is how the emergency preparedness planning process should work when multiple agencies and/or contractors are involved with a dynamic, constantly shifting public health emergency.

Clearly, we must balance the need to develop new survey procedures and research with the requirements to maintain trend data using more “traditional” or “standard” methods. Any major post-event changes to content and/or procedures of population-based surveillance systems should be considered with great caution. Changes should be implemented only rarely, or they could negatively impact the credibility of the entire system. If new survey procedures were implemented as a result of a catastrophic event, later consideration would need to be given to when to switch back to the “old” procedures. What is the “tipping point” for this decision? If a survey must cease data collection as the result of a disaster, when should it be restarted, and how does this vary by disaster type? What criteria should be used to trigger this action?

Ethics

Ethical considerations are difficult enough to solve in a traditional and fairly stable survey environment but are much more challenging when responding during a dynamic and potentially dangerous situation. For example, is it acceptable to send data collectors into dangerous situations for which they may not be fully prepared? What are the drug and/or vaccine distribution and prioritization procedures for at-risk and vulnerable populations, especially if these supplies are in short supply? How should data collectors respond if respondents erroneously believe that federal statistical agencies share data? Survey researchers also should consider the ethics of mandatory and possibly severe population-based exposure control measures, such as quarantine in the case of pandemic influenza, and the impact this scenario would have on the movement of *both* survey respondents and data collectors. Ethical responses to the possibility of retraumatizing a respondent by asking sensitive questions or questions that cause him/her to remember or "relive" the traumatic situation also need to be addressed.

THE CURRENT STATE OF THE FIELD

Adjusting to the Uncertainty of the Environment with Adaptive Designs

The preponderance of findings overwhelmingly leads to a key conclusion: survey mechanisms, production and post-production systems, and survey staff must be flexible and creative and work collaboratively when a disaster or disruption occurs during data collection. Statisticians have embraced this credo through the development of adaptive sampling designs, which were developed to efficiently provide greater coverage of a target population in an emergency by "linking" sample elements to each other. Examples include "link-tracing designs" such as network sampling, snowball sampling, chain-referral sampling, respondent driven sampling, random walk designs, adaptive cluster sampling, and "active set adaptive designs" (Katzoff, 2004).

Do Not Repudiate the Power of "More Seasoned" Proven Methods

A somewhat surprising finding in several papers was that RDD survey designs worked well in certain disaster situations even with massive infrastructure damage. In the case of Hurricane Katrina, local telephone carrier Bell South used call-forwarding technology to provide "seamless" service for its landline and cellular customers no matter where they relocated. Researchers use RDD survey designs in disaster situations for the same reasons they use them in a "normal" survey: efficiency and relatively low cost. However, RDD designs obviously are completely dependent upon the infrastructure status and mitigation strategies that might be employed. This finding may or may not apply to other disaster situations.

FUTURE RESEARCH OPPORTUNITIES

The Role of a Survey during & after the Precipitating Event

A most basic question is the role of a population-based survey in the disaster and post-disaster periods. What are the critical data elements to be collected, and do they vary by disaster type? What elements should be included in an omnibus survey? Do current baseline data exist? Who makes these decisions? What if no baseline data exist? How should we measure long-term impacts? For example, focused data collection and surveillance systems could be used to provide survivors and first responders the most up-to-date information to help identify opportunities for direct and indirect assistance while helping the largest number of persons. A survey also could be used to estimate the population at risk (e.g., not vaccinated). However, these examples only consider the use of currently existing surveillance infrastructures. How and when should an existing survey infrastructure be used versus developing a new system?

Definitions

A more precise definition of what constitutes a "public health emergency" needs to be synthesized because fulfillment of the definition will trigger implementation of an emergency public health response. In essence, when does an important public health data need become an *immediate* data need? Who makes this decision, especially if the survey covers multiple topical areas or if multiple agencies or contractors are involved in the same survey?

Identifying & Pursuing Research Projects by Collaborating with Researchers in "New" Fields

Disasters introduce a myriad of seemingly unsolvable problems, especially if a survey is being fielded or about to go into the field. Addressing these various problems will require a dedicated, timely, and multidisciplinary approach. For example, survey/mathematical statisticians and survey directors may need to interact with experienced personnel in "new" fields—disaster research, emergency/first responders, terrorism experts, life sciences, etc. Even within the field of survey methodology, researchers need to work together to generate new information on how disasters and emergency preparedness efforts impact surveillance from multiple survey-related viewpoints (cognitive, statistics, etc.). We also must consider how to build a "best practices" literature on preplanning, implementation during an event, and post-disaster evaluation to minimize duplication of effort.

Survey Estimates, Statistical Adjustments, & Data Quality

More research is needed on the potential impact of a disaster on all survey estimates, but particularly for estimates that are trended over time and/or are of critical importance. How can we control statistically for these stochastic and disruptive disasters? Do we need to develop new methods or definitions to address potential “new” sources of bias and nonresponse? For example, if a household simply does not exist anymore at an address because of a catastrophic hurricane, should this case be classified as nonresponse, or do we need a new definition, since we actually do not know if the person(s) in the household would have said “no” if asked to participate? We may need to consider developing “nuanced” definitions, new disposition codes, response rate calculations, and estimation procedures to account for these uncertainties (as best we can). Other areas of research include delineating bias implications based on the level of response or lack thereof, the impact of the interview setting on responses (such as lack of privacy in a shelter or being interviewed in someone else”s home), the influence of self-and proxy-reporting mechanisms on estimates in disaster situations, and how to best characterize the propensity of a respondent to respond post-disaster, especially if multiple sequential interviews are involved to complete the survey. Another key data quality issue is ensuring responsible use of data that may be of dubious quality, since normal quality control procedures may need to be altered or suspended to accelerate data collection and release of time-sensitive data. Further, we must consider how to communicate with data users after an event, particularly in situations where multiple disparate estimates may exist from various surveys or the data producers and/or users also were forced to evacuate.

Post-disaster Implementation Issues

In this session, participants continually revisited the practical, logistical, and administrative issues of survey research and implementation, in part because so little is known about these topics in a disaster situation. Perhaps some of these issues are best solved by developing comprehensive “continuity of operations” or “continuity of government” plans, but others may be optimally resolved through sound methodological research plans. Additionally, processing, editing, and standardized Web-based reporting and data distribution systems may facilitate or solve some of these implementation issues. However, the utility of this suggestion also depends on the nature of the event—it would not be possible if the Internet or computer networks were obliterated.

Multiple researchers identified a need for solutions to two issues that could be addressed prior to a disaster: (1) the development of even speedier review mechanisms than the traditional “expedited” or “emergency review” processes to address Office of Management and Budget

(OMB) and Institutional Review Board (IRB) clearance requirements for federally sponsored surveys, and (2) developing timely contract modification mechanisms to allow for flexible, rapid data collections should an event occur.

In a post-disaster world, survey staff should expect low compliance and difficulty tracking respondents, particularly if persons already belong to a hard-to-reach subpopulation, and problems initially contacting, inviting, and/or reminding respondents to complete a new survey, especially if respondents are more concerned about their immediate survival at the time of contact. However, some anecdotal evidence suggests that respondents may be *more* willing to respond so they can express their opinions and engage in a substantive and perhaps reassuring conversation. More research is needed on cognitive and theoretical aspects of survey participation and response in a crisis situation.

CONCLUSION

Sadly, it is only a matter of time before we will need to react to issues raised in this session in the aftermath of a disaster or disruptive event. Although these topics may seem overwhelming, we must reflect upon the sentiment expressed in a famous quote from Albert Einstein: "In the middle of difficulty lies opportunity." We are in fact wrestling with difficult issues, but our real challenge is to harness momentum from these nascent research opportunities. If we can learn how to minimize disruptive shocks to survey systems and instill a more proactive perspective, we will be doing the field a great service. Survey methods practitioners and researchers have solved difficult (even seemingly unsolvable) problems in the past; thus, as a field, we should look forward to the future and embrace these new opportunities to solve important and challenging problems.

REFERENCE

Katzoff, M. (2004). Applications of adaptive sampling procedures to problems in public health. *Proceedings of the Statistics Canada Symposium 2004: Innovative methods for surveying difficult-to-reach populations*. Retrieved May 17, 2007, from www.statcan.ca/english/freepub/11-522-XIE/2004001/Katzoff_eng_final.pdf

ADDITIONAL RESOURCES

WEB SITES (URLs accurate as of March 28, 2007; nonexhaustive list):

International Research Committee on Disasters
www.udel.edu/DRC/IRCD.html

University of California, Los Angeles
Center for Public Health and Disasters
www.cphd.ucla.edu/

University of Colorado at Boulder
National Hazards Center
www.colorado.edu/hazards

University of Delaware
Disaster Research Center
www.udel.edu/DRC/

University of Michigan
School of Public Health, Disaster Research Center
www.sph.umich.edu/drem/ or www.disasterresearch.org

University of New Orleans
Center for Hazard Assessment and Response Technology
www.chart.uno.edu/

University of Pennsylvania
Wharton School of Business, Risk Management and Decision Processes Center
http://opim.wharton.upenn.edu/risk/index.html

DISASTER-SPECIFIC PEER-REVIEWED JOURNALS (nonexhaustive list):

Disasters

International Journal of Mass Emergencies and Disasters (IJMEAD)

Prehospital Disaster Medicine

PEER-REVIEWED JOURNAL, NEWSPAPER, OR MAGAZINE ARTICLES (nonexhaustive list):

Baggett, J. (2006, April). Florida disasters and chronic disease conditions [Letter to the editor]. *Preventing Chronic Disease* [serial online]. Retrieved May 17, 2007, from www.cdc.gov/pcd/issues/2006/apr/05_0230.htm

Becker, S. M. (2004). Emergency communication and information issues in terrorist events involving radioactive materials. *Biosecurity and Bioterrorism: Biodefense Strategy, Practice, and Science, 2,* 195–207.

Boscarino, J. A., Figley, C. R., Adams, R. E., Galea, S., Resnick, H., Fleischman, A. R., et al. (2004). Adverse reactions associated with studying persons recently exposed to mass urban disaster. *The Journal of Nervous and Mental Disease, 192,* 515–524.

Bradford, R., & John A. M. (1991). The psychological effects of disaster work: Implications for disaster planning. *Journal of*

the Royal Society of Health, 3, 107–110.

Britton, N. R. (1986). Developing an understanding of disaster. *Australian and New Zealand Journal of Sociology, 22,* 254–271.

Centers for Disease Control and Prevention. (2007). Availability of FluWorkLoss 1.0 software to estimate loss of work days during an influenza pandemic. *Morbidity and Mortality Weekly Report, 56,* 256.

Clauw, D. J., Engel, C. C., Aronowitz, R., Jones, E., Kipen, H. M., Kroenke, K., et al. (2003). Unexplained symptoms after terrorism and war: An expert consensus statement. *Journal of Occupational and Environmental Medicine, 45,* 1040–1048.

Collogan, L. K., Tuma, F., Dolan-Sewell, R., Borja, S., & Fleischman, A. R. (2004). Ethical issues pertaining to research in the aftermath of a disaster. *Journal of Traumatic Stress, 17,* 363–372.

Curran, P. S., & Miller, P. W. (2002). Psychiatric implications of chronic civilian strife or war: Northern Ireland. *Advances in Psychiatric Treatment, 7,* 73–80.

de Souza Luna, L. K, Panning, M., Grywna, K., Pfefferle, S., & Drosten, C. (2007). Spectrum of viruses and atypical bacteria in intercontinental air travelers with symptoms of acute respiratory infection. *The Journal of Infectious Diseases, 195,* 675–679.

Denis, H. (1991). The complexity of technological disaster management: Technical, sociopolitical, and scientific issues. *Industrial Crisis Quarterly, 5,* 1–18.

Dewan, S. (2006, April 18). Storm evacuees found to suffer health setbacks. *The New York Times,* pp. A1, A20.

Dimaggio, C., & Galea, S. (2006). The mental health and behavioral consequences of terrorism. In R. Davis, A. Lurigio, & A. Herman (Eds.), *Victims of crime* (3rd ed., pp. 147–160). London: Sage.

Fauci, A. S. (2006). Seasonal and pandemic influenza preparedness: Science and countermeasures. *Journal of Infectious Diseases, 194,* S73–S76.

Ford, E. S., Mokdad, A. H., Link, M. W., Garvin, W. S., McGuire, L. C., Jiles, R. B., et al (2006, April). Chronic disease in health emergencies: In the eye of the hurricane. *Preventing Chronic Disease* [serial online]. Retrieved May 17, 2007, from www.cdc.gov/pcd/issues/2006/apr/05_0235.htm

Fox, L. M., Ocfemia, C. B., Hunt, D. C., Blackburn, B. G., Neises, D., Kent, W. K., et al. (2005). Emergency survey methods in acute *Crytosporidiosis* outbreak. *Emerging Infectious Diseases, 11,* 729–731.

Garcia-Sastre, A., & Whitley, R. J. (2006). Lessons learned from reconstructing the 1918 influenza pandemic. *Journal of Infectious Diseases, 194,* S127–S132.

Galea, S., Nandi, A., Stuber, J., Gold, J., Acierno, R., Best, C. L., et al. (2005). Participant reactions to survey research in the general population after terrorist attacks. *Journal of Traumatic Stress, 18,* 461–465.

Galea, S., Vlahov, D., Resnick, H., Kilpatrick, D., Bucuvalas, M., Morgan, M. D., et al. (2002). An investigation of the psychological effects of the September 11, 2001, attacks on New York City: Developing and implementing research in the acute post-disaster period. *CNS Spectrums, 7,* 585–587, 593–596.

Germann, T. C., Kadau, K., Longini, I. M., Jr., & Macken, C. A. (2006). Mitigation strategies for pandemic influenza in the United States. *Proceedings of the National Academies of Science, 103,* 5935–5940.

Glass, R. J., Glass, L. M., Beyeler, W. E., & Min, H. J. (2006). Targeted social distancing design for pandemic influenza.

Emerging Infectious Diseases, 12, 1671–1681.

Grievink, L., van der Velden, P. G., Yzermans, C. J., Roorda, J., & Stellato, R. K. (2006). The importance of estimating selection bias on prevalence estimates shortly after a disaster. *Annals of Epidemiology, 16,* 782–788.

Halloran, M. E. (2006). Challenges of using contact data to understand acute respiratory disease transmission. *American Journal of Epidemiology, 164,* 945–946.

Hassett, A. L., & Sigal, L. H. (2002). Unforeseen consequences of terrorism: Medically unexplained symptoms in a time of fear. *Archives of Internal Medicine, 162,* 1809–1813.

Hawryluck, L., Gold, W. L., Robinson, S., Pogorski, S., Galea, S., & Styra, R. (2004). SARS control and psychological effects of quarantine, Toronto, Canada. *Emerging Infectious Diseases, 10,* 1206–1212.

Homeland Security Council, United States. (2005). *National strategy for pandemic influenza*. Retrieved May 17, 2007, from www.whitehouse.gov/homeland/nspi.pdf

Kirk, M., Tribe, I., Givney, R., Raupach, J., & Stafford, R. (2006). Computer-assisted telephone interview techniques [Letter to the editor]. *Emerging Infectious Diseases, 12,* 697–698.

Kroenke, K. (2001). Studying symptoms: Sampling and measurement issues. *Annals of Internal Medicine, 134,* 844–853.

Kumar, M. S., Murhekar, M. V., Hutin, Y., Subramanian, T., Ramachandran, V., & Gupte M. D. (2007). Prevalence of posttraumatic stress disorder in a coastal fishing village in Tamil Nadu, India, after the 2004 tsunami. *American Journal of Public Health, 97,* 99–101.

Levav, I., Novikov, I., Grinshpoon, A., Rosenblum, J., & Ponizovsky, A. (2006). Health services utilization in Jerusalem under terrorism. *American Journal of Psychiatry, 163,* 1355–1361.

Mandl, K. D., Overhage, J. M., Wagner, M. M., Lober, W. B., Sebastiani, P., Mostashari, F., et al. (2004). Implementing syndromic surveillance: A practical guide formed by early experience. *Journal of the American Medical Informatics Association, 11,* 141–150.

Mills, C. E., Robins, J. M., Bergstrom, C. T., & Lipsitch, M. (2006). Pandemic influenza: Risk of multiple introductions and the need to prepare for them. *PLoS Medicine, 3*(6), e135. Retrieved May 17, 2007, from http://medicine.plosjournals.org/perlserv/?request=get-document&doi=10.1371%2Fjournal.pmed.0030135

Norris, F. H. (2006). Disaster research methods: Past progress and future directions. *Journal of Traumatic Stress, 19,* 173–184.

Norris, F. H., Galea, S., Friedman, M. J., & Watson, P. J. (Eds.). (2006). *Methods for disaster mental health research*. New York: Guilford Press.

Norris, F. H., Slone, L. B., Baker, C. K., & Murphy, A. D. (2006). Early physical health consequences of disaster exposure and acute disaster-related PTSD. *Anxiety, Stress, and Coping, 19,* 95–110.

Norris, F. H., Friedman, M. J., Watson, P. J., Byrne, C. M., Diaz, E., & Kaniasty, K. (2002). 60,000 disaster victims speak: Part I. An empirical review of the empirical literature, 1981–2000. *Psychiatry, 65,* 207–239.

Norris, F. H., Friedman, M. J., & Watson, P. J. (2002). 60,000 disaster victims speak: Part II. Summary and implications of the disaster mental health research. *Psychiatry, 65,* 240–260.

O'Reilly, D., & Stevenson, M. (2003). Mental health in Northern Ireland: Have "the Troubles" made it worse? *Journal of Epidemiology and Community Health, 57,* 488–492.

Pandemic planning assumptions. (n.d.). Retrieved May 17, 2007 from http://pandemicflu.gov/plan/pandplan.html

Peguero, A. A. (2006). Latino disaster vulnerability: The dissemination of hurricane mitigation information among Florida's homeowners. *Hispanic Journal of Behavioral Sciences, 28,* 5–22.

Phillips, Z. (2006, November). Disaster drills: Practice doesn't make perfect. *Government Executive, 38*(19), 32–38.

Roorda, J., van Stiphout, W. A. H. J., & Huijsman-Rubingh, R. R. R. (2004). Post-disaster health effects: Strategies for investigation and data collection. Experiences from the Enschede firework disaster. *Journal of Epidemiology and Community Health, 58,* 982–987.

Silver, R. C. (2004). Conducting research after the 9/11 terrorist attacks: Challenges and results. *Families, Systems, & Health, 22,* 47–51.

Silver, R. C. (2002, May/June). Conducting research following community traumas: Challenges, pitfalls, and results. *Psychological Science Agenda, 15*(3), 8–9.

Vazquez, A. (2007). Epidemic outbreaks on structured populations. *Journal of Theoretical Biology, 245,* 125–129.

Vlahov, D., & Galea, S. (2004). Epidemiologic research and disasters. *Annals of Epidemiology, 14,* 532–534.

Vucetic, S., & Sun, H. (2006). *Aggregation of location attributes for prediction of infection risk.* Proceedings of the 2006 SIAM Conference on Data Mining. Retrieved May 17, 2007, from www.siam.org/meetings/sdm06/workproceed/Spatial%20Data%20Mining/SDM4.vucetic_siam06.pdf

Wray, R., & Jupka, K. (2004). What does the public want to know in the event of a terrorist attack using plague? *Biosecurity and Bioterrorism: Biodefense Strategy, Practice, and Science, 2,* 208–215.

Yzermans, C. J., Donker, G. A., Kerssens, J. J., Dirkzwager, A. J. E., Soeteman, R. J. H., & ten Veen, P. M. H. (2005). Health problems of victims before and after disaster: A longitudinal study in general practice. *International Journal of Epidemiology, 34,* 820–826.

INTRODUCTION TO SESSION 2: Measurement Errors and Health Disparities

Timothy P. Johnson, *University of Illinois at Chicago*

The importance of survey research to understanding population health, health behaviors, and health care access is as important today as back during the time of the first Health Survey Research Methods Conference in 1975.

Concern regarding the quality of health survey data has played no small role in the genesis of these conferences. This session continues that focus by examining issues of measurement error in the assessment of health disparities.

As you're all aware, the past decade has witnessed a growing emphasis on assessment of health disparities in America and exploration of public policies designed to ameliorate them.

Because many of the documented disparities are based on analyses of survey data, an important question that has to date received little attention is the degree to which the disparities being documented represent disparities in health conditions or disparities in the quality of the survey data being collected across subgroups of respondents.

Interestingly, some recent analyses suggest the presence of disparities in the efficacy of some basic survey question design principles, such that adherence to these basics of question construction might improve overall question comprehension but also, ironically, increase group differences in comprehension across racial and ethnic groups (Johnson et al., 2006).

This potential problem is reminiscent of the recognition some 15 years ago that not all findings from the famous Framingham Study were generalizable to women and minority populations, a recognition that contributed to the NIH Revitalization Act of 1993[Note] and the funding of studies designed to examine cardiovascular processes and risk factors among non-White and nonmale populations.

So I guess it is worth asking if we can continue to assume that all of the elements of good questionnaire design and practice that were developed in the decades after World War II, using data collected from samples of very homogeneous white populations, are equally generalizable to non-White and immigrant populations? Or is it time to reconsider some of our conventional wisdom?

The increasing diversity of our population, the recognition that the benefits of good health are not equally distributed among all citizens, and the growing evidence that there may also be disparities in the quality of our health measures, thus serve as the framework for the papers in this session.

REFERENCE

Johnson, T. P., Cho, Y. I., Holbrook, A. L., O'Rourke, D., Warnecke, R., & Chávez, N. (2006). Cultural variability in the effects of survey question design features on respondent comprehension. *Annals of Epidemiology*, *16*, 661–668.

FOOTNOTE

[Note] Public Law 103-43. National Institutes of Health Revitalization Act of 1993, 42 USC 289 (a)(1).

FEATURE PAPER: Measurement Equivalence for Three Mental Health Status Measures[Note]

John A. Fleishman, *Center for Financing, Access, and Cost Trends, Agency for Healthcare Research and Quality*

INTRODUCTION

A number of large-scale population-based surveys have investigated the sociodemographic correlates of mental health and illness (Kessler, Berglund et al., 2003). Many of these studies attempt to gauge the prevalence of specific psychiatric disorders by using structured interview protocols, which yield dichotomous indicators of mental disorder. Other studies administer questions about specific symptoms, typically depression and anxiety, that place respondents along a continuum of symptom severity (Radloff, 1977; Ware, Kosinski, Turner-Bowker, & Gandek, 2002). In what follows, we will be concerned with symptom scales that assess mood disorder (depression); other forms of mental disorder, such as psychoses or addictive disorders, are not considered.[1]

As research has accumulated (Burdine, Felix, Abel, Wiltraut, & Musselman, 2000; Kessler, Berglund et al., 2003; Kessler & Zhao, 1999), the results support several empirical generalizations about the association of depression and sociodemographic characteristics. For example,

- Rates of depression are higher in younger people (18–44) than in older groups (60+).
- Women report more symptoms of depression than men.
- Those with less than high school education have higher rates of affective and anxiety disorders than those with 16 or more years of schooling.
- Findings regarding racial differences are less consistent. The National Comorbidity Study found lower rates of mood disorders among Blacks than non-Hispanic Whites, but the National Comorbidity Study Replication (NCS-R) reported slightly but not significantly higher rates of major depression. Hispanics had higher rates of major depression than non-Hispanic Whites in the NCS-R.

Each of these generalizations involves comparing two or more sociodemographic groups with respect to a measure of mental health. For such comparisons to be valid, the measure of mental health or illness must be *equivalent* in the different groups. If some questions are interpreted differently by members of different groups, or if extraneous factors affect responses in some groups but not in others, the lack of measurement equivalence will confound group comparisons and threaten the validity of conclusions.

The goal of this study is to demonstrate the use of multiple-indicator multiple-cause (MIMIC) models to assess measurement equivalence. We apply MIMIC models to a set of 10 items that assess psychological distress and examine the extent to which these items show measurement equivalence across groups defined by sociodemographic characteristics.

DIFFERENTIAL ITEM FUNCTIONING

It is useful to think of measurement as attempting to obtain quantitative information regarding an unobserved (or latent) variable. The latent variable can be a construct that is difficult or impossible to measure directly, such as depression. However, we can make inferences regarding the latent variable based on patterns of relationships among observed indicators, such as questions asking about specific symptoms. In many measurement applications, we are conceptually interested in group differences in a latent variable. We want group differences in observed variables (e.g., score on a depression symptom scale) to faithfully reflect the mean differences in latent variables. This will not happen if measures are not equivalent in the different groups.

Differential item functioning (DIF) is another name for measurement nonequivalence. Note that a group difference in observed variables does not, per se, indicate DIF. DIF is present if there are group differences in observed indicators *over and above* group differences in the latent variable (Millsap & Everson, 1993). DIF can be represented in terms of parameters of a factor analysis model:

$$Y_{ij} = t_j + \lambda_j \xi_i + \varepsilon_{ij},$$

where Y_{ij} is person *i*'s observed score on item *j*; τ_j is a threshold; ξ_i represents the (unobserved) factor score; λ_j is the loading of item *j* on the factor, and ε_{ij} is an error term. (For items with ordered categorical response scales, such as Likert scales, there are multiple threshold parameters —one less than the number of response categories. A threshold indicates the point that separates two adjacent response options.) For measurement equivalence across groups, the values of the threshold (τ_j) and the loading (λ_j) must be the same for members of different groups. If the threshold and loading parameters vary from group to group, then DIF is present, and observed group differences cannot be attributed exclusively to differences in the distribution of ξ_i.

The multiple-indicator multiple-cause (MIMIC) model extends the factor model by incorporating additional exogenous variables, which are assumed to influence the latent factor (Muthen, 1989). The model can be represented by two equations:

$$Y_{ij} = \tau_j + \lambda_j \xi_i + \kappa x + \varepsilon_{ij},$$

$$\xi_i = \gamma x + \zeta.$$

The first equation adds direct effects (κ) of covariates (x) to the model for responses to a questionnaire item. The second equation specifies that the underlying factor is affected by covariates (γx) and a residual (ζ). Covariates indicate membership in specific (e.g., demographic) groups.

The basic MIMIC model says that group differences will be observed in the items because covariates affect latent mental health, which then influences responses to observed items. If DIF is absent, controlling for the underlying factor, there are no sociodemographic differences in responses to the observed items. DIF is incorporated by adding direct effects from the covariates to the observed indicators, unmediated by the latent factors. The κx term in the equation above represents a "DIF effect." By estimating parameters corresponding to these direct effects, one can statistically control for them and then examine the other parameters of more substantive interest–specifically, the effects of the covariates on the factor (i.e., sociodemographic variables on mental health). This approach has been used to examine DIF in measures of depression, functional disability, and cognitive functioning (Fleishman & Lawrence, 2003; Fleishman, Spector, & Altman, 2002; Gallo, Anthony, & Munthen, 1994; Grayson, Mackinnon, Jorm, Creasey, & Broe, 2000; Jones, 2006; Jones & Gallo, 2002).

METHODS

Medical Expenditure Panel Survey (MEPS)

The MEPS is a nationally representative survey of health care utilization and expenditures for the U.S. noninstitutionalized civilian population, supported by the Agency for Healthcare Research and Quality (AHRQ). Current analyses use data collected in 2004.

The MEPS household component core interview collects detailed data on sociodemographic characteristics of each household member. For this analysis, education was categorized as less than high school, high school graduate, or at least some college. Age was categorized as 18–40, 41–50, 51–60, 61–70, 71–80, or 81 and older. Race/ethnicity was coded as White (non-Hispanic), Black (non-Hispanic), Hispanic, and other. Binary indicators represented these categories and female gender.

A self-administered questionnaire (SAQ) obtained information that could be unreliable if reported by a proxy. For analyzing questionnaire data, special weights were developed incorporating adjustments for questionnaire nonresponse (AHRQ, 2002). Ten SAQ items assessed psychological distress, as reflected in feelings of depression or anxiety.

The questionnaire included Version 2 of the widely used SF-12 Health Survey (Ware et al., 2002). The mental health subscale comprised two items asking about frequency of feeling "calm and peaceful" and "downhearted and depressed." The SAQ also included the K6 scale to measure nonspecific psychological distress (Kessler, Barker et al., 2002; Kessler et al., 2003). Using a 30-day reference period, respondents rated how often they felt "nervous," "hopeless," "restless or fidgety," "so sad that nothing could cheer you up," "that everything was an effort," and "worthless." The response scale ranged from 4 (*all the time*) to 0 (*none of the time*), with higher scores indicating greater distress. The two-item Patient Health Questionnaire (PHQ-2), designed as a brief depression screener (Kroenke, Spitzer, & Williams, 2003; Lowe, Kroenke, & Grafe, 2005), asked "Over the last 2 weeks, how often have you been bothered by any of the following problems?" The problems were "feeling down, depressed, or hopeless" and "little interest or pleasure in doing things." Responses ranged from 0 (*not at all*) to 3 (*nearly every day*).

ANALYSES

The analytic sample included those respondents who were eligible to receive the SAQ and completed the questionnaire themselves. The total unweighted sample size for the 2004 MEPS was 34,403 persons, of whom 23,395 were eligible to receive the SAQ. Persons younger than 18, institutionalized, or in the military were ineligible for the SAQ. Of those eligible to receive the questionnaire, 93% responded (*n*=21,752). Because the SF-12, K6, and PHQ-2 may be inaccurate if reported by a proxy, we restricted the analyses to respondents who completed the questionnaires themselves (or with the aid of the interviewer); this reduced the eligible sample to 19,008. A further 47 respondents were removed because they had missing data on all SAQ items, and 188 were excluded due to missing data for education. The final analytic sample included 18,843 respondents.

For preliminary analyses, we combined the ten items into a summary scale. Because most of the items tap nonspecific psychological distress, we refer to this as the PD scale. We next estimated several MIMIC models using the ten individual items. The "no-DIF" model constrained all possible parameters representing DIF effects to equal zero. Models with DIF allowed selected DIF parameters to be freely estimated. The MIMIC model is one kind of structural equation model. We evaluated the fit of no-DIF and DIF models using several criteria that often are used to evaluate the fit of structural equation models. A goodness-of-fit statistic, reflecting the discrepancy between the observed data (item means and covariances) and the model's predictions, can be referred to a chi-square distribution. However, because statistical power increases with sample size, chi-square goodness-of-fit tests in large samples should be viewed with caution because trivial differences often appear statistically significant. Consequently, we also examined other indicators of goodness-of-fit. The Comparative Fit Index (CFI) and the Tucker-Lewis Index (TLI) compare the substantive model to a baseline null model of independence among the observed variables; values of 0.95 or higher (with a maximum of 1.0) suggest acceptable fit (Hu & Bentler, 1999). The Root Mean Square Error of Approximation (RMSEA) assesses misfit per degree of freedom; values less than 0.08 suggest an acceptable fit, while values less than 0.05 suggest very good fit (Browne & Cudek, 1993).

To determine which of many possible DIF effects merited closer examination, we examined expected parameter change in the no-DIF model. The expected parameter change shows the magnitude of change if a previously constrained parameter is estimated. We focused on values of expected change that exceeded an arbitrary value of 0.05. This situation exemplifies a general issue. When applying structural equation models to large samples, as are common in national surveys, criteria need to be developed for distinguishing which expected changes point to potentially important model modifications and which can be disregarded as minor deviations.

The MIMIC analyses were conducted using Mplus software (Muthen & Muthen, 1998â€“2006). Because the items had ordinal response scales with distributions that were not symmetric, weighted least squares estimation was performed based on a polychoric correlation matrix. All analyses incorporated adjustments for the complex sampling design of the MEPS.

Table 1. Mean PD Scores, by Demographic Characteristics

CHARACTERISTIC	Weighted Proportion	Mean PD Score
Gender: Female	0.54	18.40
Gender: Male	0.46	15.36
Education: < High school	0.17	21.56
Education: High school	0.32	17.18
Education: Some college	0.50	14.86
Race/Ethnicity: White	0.71	16.68
Race/Ethnicity: Black	0.11	17.62
Race/Ethnicity: Hispanic	0.12	17.97
Race/Ethnicity: Other	0.06	17.67
Age group: 18–40	0.43	16.73
Age group: 41–50	0.21	18.13
Age group: 51–60	0.16	17.93
Age group: 61–70	0.10	15.10
Age group: 71–80	0.07	15.48
Age group: 81+	0.03	18.07

N = 18,190 cases without missing data.
Analyses based on weighted data.
SOURCE: Center for Financing Access and Cost Trends, AHRQ, MEPS Household Component, 2004.

RESULTS

Table 1 shows unadjusted mean psychological distress scores for different sociodemographic categories. Women had higher PD scores than men. For education, PD was lower for more highly educated groups. For age, PD was higher for those in the 41–60 age range than for younger people, but PD scores dropped for those between 60–80 years old. Racial/ethnic differences in PD were not significant.

MIMIC Model Results

A one-factor confirmatory factor analysis (CFA) model had adequate fit to the data in terms of CFI and TLI (0.965 and 0.992, respectively), but the RMSEA value (0.083) was somewhat high. The residual correlation between the items "nervous" and "restless" was extremely high. These two items focus more on anxiety symptoms, while the others are more oriented to depression. The model was re-estimated to include this correlation. The revised model had improved fit (CFI = 0.978, TLI = 0.995, RMSEA = 0.065). The factor loadings were all substantial and significant. The lowest loading was for "calm and peaceful" (.321). All subsequent analyses incorporated the residual correlation between "nervous" and "restless."

The CFA model was expanded to a MIMIC model by including effects of gender, race/ethnicity, education, and age on a latent PD factor. The no-DIF model did not include direct effects from sociodemographic variables to individual items. Although the chi-square was significant (χ^2 = 1705.15, *df* = 59), other fit indices were acceptable (CFI = 0.985, TLI = 0.994, RMSEA = 0.038). If strong DIF effects were present, the no-DIF model would fit the data poorly. On the basis of these fit indices, one would have some justification for concluding that DIF was not substantially distorting the results.

Nevertheless, we examined expected parameter changes to determine where the model could be improved. Three items—"depressed," "down," and "worth"—had no potential DIF effects associated with standardized expected parameter change of 0.05 or higher. These three items constituted an "anchor" without DIF. To identify a model with DIF effects, at least one item (and preferably more) must be assumed to have no DIF. The remaining items had one or more instances of standardized expected parameter change above 0.05. The "maximal" DIF model included direct effects from all sociodemographic variables to each of these latter items, adding a total of 77 parameters to the no-DIF model (i.e., 7 items times 11 indicators of sociodemographic variables).

Adding parameters representing DIF effects improved model fit slightly (χ^2 = 1596.98, *df* = 35). The CFI improved marginally (0.986), but the TLI and RMSEA became slightly worse (0.990 and 0.049, respectively), probably due to incorporating a number of direct effects of small magnitude.

Table 2. Effects of Demographic Variables on Psychological Distress in MIMIC Models

VARIABLE	No DIF	Maximal DIF	Selective DIF
Female	0.514 (.041)*	0.624 (.050)*	0.574 (.045)*

Black	-0.065 (.083)	-0.020 (.104)	-0.078 (.094)
Hispanic	-0.088 (.061)	0.114 (.077)	0.116 (.075)
Other race	0.122 (.095)	0.151 (.114)	0.020 (.110)
Age 41–50	0.232 (.064)*	0.325 (.077)*	0.259 (.071)*
Age 51–60	0.239 (.066)*	0.364 (.081)*	0.268 (.074)*
Age 61–70	-0.274 (.081)*	-0.257 (.092)*	-0.305 (.090)*
Age 71–80	-0.292 (.087)*	-0.339 (.100)*	-0.437 (.096)*
Age 81+	0.068 (.137)	0.133 (.158)	-0.028 (.156)
No high school degree	1.046 (.062)*	1.198 (.073)*	1.169 (.069)*
High school degree	0.451 (.053)*	0.525 (.064)*	0.505 (.060)*

N=18,843. Analyses based on weighted data. Standard errors in parentheses.
*Ratio of parameter to standard error exceeds 2.0.

This version of a model incorporating DIF could be considered a maximal adjustment, as all possible DIF effects were included for each nonanchor item. We also estimated a model that included only "major" DIF effects. A major DIF effect was defined as one with a parameter of 0.300 or higher in the DIF model. Again, this criterion represents an arbitrary cutoff, and this is an area in which more methodological work is needed. The fit indices for this "selective" DIF model were CFI = 0.987, TLI = 0.994, RMSEA = 0.037. The differences in fit between this model and the no-DIF model were minimal.

Comparing estimated group differences in models with DIF effects and models without is one method of gauging the *impact* of DIF. If incorporating DIF effects produces substantial changes in the associations of covariates with the factor, then DIF is confounding group differences. Table 2 shows the coefficients for the effects of sociodemographic variables on the latent PD factor in the MIMIC models. In this case, the pattern of significant coefficients is similar across the no-DIF, "maximal" DIF, and "selected" DIF models, although there are slight differences in the magnitudes of coefficients. In light of the fact that the no-DIF model had acceptable fit, this is not surprising. In the present case, the impact of DIF appears to be minimal.

Table 3 shows direct effects that were above .300 in absolute value in the "selected" DIF model. It is noteworthy that gender and education had no direct effects above this threshold, suggesting an absence of DIF due to these characteristics. DIF as a result of age was concentrated in the oldest age groups. It is consistent with common sense to see that people over 70 are more likely to report that everything is an effort, controlling for psychological distress; this is probably a reflection of age-related decrements in physical capability. For Blacks and Hispanics, some DIF effects were positive and others were negative; this could result in such effects canceling out in their impact on overall observed PD scale scores. DIF effects were most frequent for Hispanic respondents. This may reflect issues in translating the items or differences in cultural interpretations of the items among Hispanics. These patterns deserve consideration in future research.

Table 3. Direct Effects (DIF) of Demographic Variables on Nonachor Items

ITEM	Female	Age 41–50	Age 51–60	Age 61–70	Age 71–80	Age 81+	Black	Hispanic	Other Race	< High School	High School Degree
Calm/peaceful	-	-	-	-	-	-0.335	-	-0.395	-	-	-
Nervous	-	-	-	-	-	-	-0.307	-0.213	-	-	-
Hopeless	-	-	-	-0.218	-	-	0.306	0.429	-	-	-
Restless	-	-	-	-	-	-	-	-0.367	0.232	-	-
Sad	-	-	-	-	-	-	0.290	0.288	0.391	-	-
Effort	-	-	-	-	0.438	0.629	-	-0.210	-	-	-
Interest	-	-	-	-	0.473	0.463	0.360	-	0.349	-	-

DISCUSSION

The results provide reassurance regarding potential measurement equivalence in these items assessing psychological distress. Overall, DIF does not appear to be seriously biasing comparisons of sociodemographic groups in terms of psychological distress. The fit of a model constraining DIF effects to be zero was adequate, and models that incorporated DIF effects fit slightly but not substantially better than the no-DIF model. Models with and without DIF yielded similar patterns of estimated group differences in psychological distress. The initial development of the K6 scale examined consistency of item parameters across age, gender, race/ethnicity, and education subgroups; items showing evidence of DIF were excluded from further consideration (Kessler et al., 2002). The current results extend and replicate the developmental scale analyses, showing essential measurement equivalence across sociodemographic groups in a new data set.

If some items are found to have substantial DIF, the researcher must decide how to deal with this potential bias. Incorporating parameters that reflect DIF into larger statistical models, thereby adjusting for DIF when making more substantively important comparisons, provides a potentially more practical approach for secondary analyses of survey data, compared to removing nonequivalent items. Advantages of the MIMIC model approach include the following: (1) Comparing estimated effects of key variables when controlling for and not controlling for DIF provides an intuitive sense of the extent to which DIF may be distorting substantively important comparisons, and (2) Multiple groups can be examined simultaneously. One major disadvantage of the MIMIC model is that the model assumes that the loadings of the observed variables on the latent factor(s) are the same in all groups. Multiple-group MIMIC modeling can address this issue.

To examine DIF, we combined items from three instruments. This was necessary to estimate the underlying factor when assessing DIF. However, for comparability with prior research, we do not suggest that these items be combined to create a new measure of psychological distress. Although DIF effects were not substantial in these analyses, this may not be the case for other measures and other group comparisons, and analysts need to be aware of possible biases introduced by nonequivalent measures.

REFERENCES

Agency for Healthcare Research and Quality. (2002). *PUF documentation files: MEPS HC-0089, 2004 full-year consolidated data file.* Rockville, MD: Author. Retrieved January 29, 2007, from www.meps.ahrq.gov/mepsweb/data_stats/download_data_files_detail.jsp?cboPufNumber=HC-089

Browne, M. W., & Cudeck, R. (1993). Alternative ways of assessing model fit. In K. A. Bollen & J. S. Long (Eds.), *Testing structural equation models* (pp. 136–162). Thousand Oaks, CA: Sage.

Burdine, J. N., Felix, M., Abel, A., Wiltraut, C., & Musselman, Y. (2000). The SF-12 as a population health measure: An exploratory examination of potential for application. *Health Services Research, 35,* 885–904.

Fleishman, J. A., & Lawrence, W. F. (2003). Demographic variation in SF-12 scores: True differences or differential item functioning. *Medical Care, 41,* III-75–III-86.

Fleishman, J. A., Spector, W. D., & Altman, B. M. (2002). Impact of differential item functioning on age and gender differences in functional disability. *Journals of Gerontology: Social Sciences,57*(B), S275–S284.

Gallo, J. J., Anthony, J. C., & Muthen, B. O. (1994). Age differences in the symptoms of depression: A latent trait analysis. *Journals of Gerontology: Psychological Sciences, 49,* P251–P264.

Grayson, D. A., Mackinnon, A., Jorm, A. F., Creasey, H., & Broe, G. A. (2000). Item bias in the Center for Epidemiologic Studies Depression Scale: Effects of physical disorders and disability in an elderly community sample. *Journals of Gerontology: Psychological Sciences, 55B,* P273–P282.

Hu, L. T., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling, 6,* 1.

Jones, R. N. (2006). Identification of measurement differences between English and Spanish language versions of the Mini-Mental State Examination: Detecting differential item functioning using MIMIC modeling. *Medical Care, 44,* S124–S133.

Jones, R. N., & Gallo, J. J. (2002). Education and sex differences in the Mini-Mental State Examination: Effects of differential item functioning. *Journals of Gerontology: Psychological Sciences, 57B,* P548–P558.

Kessler, R. C., Andrews, G., Colpe, L. J., Hiripi, E., Mroczek, D. K., Normand, S.-L. T., et al. (2002). Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychological Medicine, 32,* 959?976.

Kessler, R. C., Barker, P. R., Colpe, L. J., Epstein, J. F., Gfroerer, J. C., Hiripi, E., et al. (2003). Screening for serious mental illness in the general population. *Archives of General Psychiatry, 60,* 184–189.

Kessler, R. C., Berglund, P., Demler, O., Jin, R., Koretz, D., Merikangas, K. R., et al. (2003). The epidemiology of major depressive disorder: Results from the National Comorbidity Survey Replication (NCS-R). *Journal of the American Medical Association, 289,* 3095–3105.

Kessler, R. C., & Zhao, S. (1999). Overview of descriptive epidemiology of mental disorders. In C. S. Aneshensel & J. Phelan (Eds.), *Handbook of the sociology of mental health*. New York: Kluwer Academic/Plenum.

Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2003). The Patient Health Questionnaire-2: Validity of a two-item depression screener. *Medical Care, 41,* 1284–1292.

Lowe, B., Kroenke, K., & Grafe, K. (2005). Detecting and monitoring depression with a two-item questionnaire (PHQ-2). *Journal of Psychosomatic Research, 58,* 163–171.

Millsap, R. E., & Everson, H. T. (1993). Methodology review: Statistical approaches for assessing measurement bias. *Applied Psychological Measurement, 17,* 297.

Muthen, B. O. (1989). Latent variable modeling in heterogeneous populations. *Psychometrika, 54,* 557–585.

Muthen, L. K., & Muthen, B. O. (1998–2006). *Mplus user's guide* (4th ed.). Los Angeles: Muthen and Muthen.

Radloff, L. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1,* 395–401.

Ware, J. E., Kosinski, M., Turner-Bowker, D. M., & Gandek, B. (2002). *SF-12v2: How to score Version 2 of the SF-12 Health Survey.* Lincoln, RI: QualityMetric, Inc.

[Note] The opinions expressed in this article are those of the author. No official endorsement of the Agency for Healthcare Research and Quality or the Department of Health and Human Services is intended or should be inferred.

FEATURE PAPER: Reliability and Validity of a Colorectal Cancer Screening (CRCS) Questionnaire by Mode of Survey Administration

Sally W. Vernon, *University of Texas–Houston*
Jasmin A. Tiro, *National Cancer Institute*
Rachel W. Vojvodic, Sharon P. Coan, and Pamela M. Diamond, *University of Texas–Houston*
Anthony Greisinger, *Kelsey Research Foundation*

INTRODUCTION

Valid and reliable self-report measures of cancer screening behaviors are important for (1) identifying correlates and predictors of behavior, (2) evaluating the effectiveness of behavioral interventions, and (3) monitoring progress and trends in adherence to cancer screening guidelines (Hiatt, Klabunde, Breen, Swan, & Ballard-Barbash, 2002; Vernon, Briss, Tiro, & Warnecke, 2004). The implementation of federal legislation limiting access to medical records (Health Insurance Portability and Accountability Act of 1996 [HIPAA]) is likely to increase the need to use self-reported data in epidemiologic, health services, and behavioral research studies. For colorectal cancer screening (CRCS), assessing the accuracy of self-reports is especially difficult because there are multiple types of acceptable screening tests (i.e., fecal occult blood test [FOBT], sigmoidoscopy [SIG], colonoscopy [COL], and barium enema [BE]), the recommended time interval for test completion differs within and between tests, and the guidelines have changed over time (Vernon et al., 2004). Adding to this complexity is the number of measures of utilization (e.g., initial, recent, regular, ever).

Survey items measuring CRCS on the National Health Interview Survey (NHIS) and the Behavioral Risk Factor Surveillance System (BRFSS) have differed over time and between surveys. There is one test-retest reliability study on CRCS for the BRFSS (Bradbury, Brooks, Brawarsky, & Mucci, 2005), but we know of no studies validating CRCS questions used in these national surveys. Yet these measures frequently are adapted by investigators conducting descriptive and intervention studies.

In 1999, the National Cancer Institute (NCI) convened a group of experts to develop uniform definitions and measures to assess CRCS behaviors (hereafter called the NCI CRCS questionnaire) (Vernon, Meissner et al., 2004). The initial draft of the NCI CRCS questionnaire underwent cognitive testing as part of the development of NCI's Health Information National Trends Survey in 2003. Qualitative data from focus groups (Bastani, Gallardo, & Maxwell, 2001; Beeker, Kraft, Southwell, & Jorgensen, 2000; Goel et al., 2004; Weitzman, Zapka, Estabrook, & Goins, 2001) showed that many adults do not know or recognize the names of CRCS tests and that many were unable to distinguish between SIG and COL or between home-based and office-based FOBT (Baier et al., 2000; Madlensky, McLaughlin, & Goel, 2003); therefore, the cognitive interviews focused on issues related to comprehension and interpretation of the questions and, to a lesser extent, on strategies respondents used to recall information. Findings from the cognitive interviews were consistent with previous data and led to a revised questionnaire and a recommendation that CRCS test descriptions be provided prior to asking questions about test use (Vernon, Meissner et al., 2004).

The purpose of the research described in this report was to evaluate the reliability and validity of three of the screening tests included in the NCI CRCS questionnaire: FOBT, SIG, and COL. A secondary objective was to determine if validity estimates are equivalent across three modes of administration (mail, telephone, and face-to-face). We focused on mode of administration because mode differences might affect comparisons of estimates from national surveys (NHIS is administered face-to-face, while BRFSS is administered over the telephone). We also evaluated, with a subsample, the test-retest reliability of the NCI CRCS questionnaire over a two-week time period.

METHODS

Study Population

This study was approved by the University of Texas Health Science Center at Houston Committee for the Protection of Human Subjects (HSC-SPH-04-111). The target population was men and women between 51 and 74 years of age who had received primary care at the Kelsey-Seybold Clinic (KSC) in Houston, Texas, for at least five years prior to being invited to participate in the study. We selected a relatively homogeneous and stable patient population in a setting with strong medical record and auxiliary data systems. Patients were excluded if they had a history of colorectal cancer. Eligibility status was determined from the KSC electronic administrative database and was verified at the time of study enrollment.

We used a case-control study design to maximize efficiency. Cases were defined as KSC patients who had a recent home FOBT, SIG, or COL recorded in the administrative database. We followed 2007 American Cancer Society (ACS) guidelines to define recency: a FOBT within the past year, or a SIG or COL within the past five years. We limited our definition of "recent COL" to the past five years because a COL received prior to becoming a KSC patient may not have been recorded in the database. Controls either never had a CRCS test or no recent CRCS test was recorded in the KSC database. Cases could have a single CRCS test or multiple tests and, therefore, could serve as a case or a control for each CRCS test type. If the case had multiple tests of a particular type (e.g., two SIGs), we used the most recent test in the database. Our goal is to collect self-report data on 200 cases and 100 controls per mode of administration (mail, telephone, and face-to-face) with at least 100 cases for each CRCS type across all modes. At the time of this report, we had collected data for the validation study from 385 cases and 201 controls.

Recruitment

Eligible cases and controls were randomly selected from the KSC database every two weeks and were mailed invitation letters describing the study and containing contact information for the Kelsey Research Foundation (KRF). Study candidates were told they could decline participation by calling the KRF; those who did not actively decline participation were called by a KRF research assistant after mailing the invitation letter. During the call, the recruiter ascertained eligibility, obtained verbal HIPAA and informed consent, and obtained consent to review the participant's medical record. Candidates were called at least six times before being classified as a nonrespondent. Patients who refused to participate were asked why they declined.

Questionnaire

We modified the format of the NCI CRCS questionnaire for mail, telephone, and face-to-face administration. We developed two versions of the questionnaire, one to be mailed with explicit instructions and detailed skip patterns, and the other to be used for telephone and face-to-face interviews with interviewer scripts and prompts. Both versions were professionally printed as eight-page color booklets that were also scannable.

Pilot testing of the mail and telephone versions of the questionnaire revealed that people were confused by the order and skip patterns of the first four questions for each CRCS test. As a result, we reordered the questions to help respondents identify and follow the skip pattern appropriate for their CRCS test history.

For each CRCS test, respondents were asked if they ever had the test, whether they had ever heard of the test, whether their physician recommended the test, the time interval of the most recent test, the month and year of the most recent test, and whether the most recent test was done at a KSC facility. We also included questions about sociodemographics (sex, age, marital status, race, ethnicity, education), use of the health care system (recency of last KSC visit, number of KSC and non-KSC visits during the past five years), family history of CRC, and social desirability. To assess social desirability, we used a short ten-question version of the Marlowe-Crowne Social Desirability Scale (Strahan & Gerbasi, 1972).

Survey Administration

Every week, names of new enrollees were sent from the KRF to project staff at the University of Texas to be randomized to survey administration mode, and a subset of those was selected for the test-retest reliability study. We followed the Dillman approach for mail surveys (Dillman, 1978). Enrollees randomized to the mail mode received a packet consisting of a letter reiterating their agreement to participate in the study, a standardized bubble-formatted questionnaire, a postage-paid envelope, and a pencil. Nonrespondents were mailed a second packet after four weeks and a final reminder postcard after eight weeks. Sixteen weeks from the enrollment date, enrollees who did not return a mail questionnaire were classified as dropouts. Enrollees randomized to the face-to-face mode were called to set up a time for an interview to be conducted at the participant's home or at the centrally located KSC main campus, depending on the preference of the study participant. Almost two-thirds of face-to-face participants (61%) chose to have their interview conducted at their homes. Enrollees randomized to the telephone and face-to-face modes were called at least six times before being classified as dropouts. If possible, messages were left requesting that the enrollee call the project's local telephone number. Participants were mailed a $20 honorarium after completing the questionnaire.

Reliability Study

A subset of enrollees who completed the questionnaire was randomly selected to complete a second survey to evaluate test-retest reliability. They were randomly assigned to one of three time intervals (two weeks, three months, or six months). Our goal is to complete 65 reliability surveys for each time interval per mode of administration (total $n = 585$). The same survey administration protocols were followed for each mode. After completing the second survey, participants were mailed another $20 honorarium. At the time of this report, reliability results were available only for the two-week follow-up ($n = 179$).

Medical Record Abstraction

We chose to combine data from the medical record and the electronic administrative database as our gold standard (hereafter referred to as the combined medical record). Recent studies have described sources of measurement error in both data sources, such as failing to include laboratory reports, delayed recording, and incomplete recordkeeping in public health care settings (Fiscella, Holt, Meldrum, & Franks, 2006; Peabody, Luck, Glassman, Dresselhaus, & Lee, 2000). Data from the electronic administrative database and medical record abstractions were merged, and duplicates were deleted. Priority was given to the administrative records for any conflicts in test type or date. We abstracted the following information for all CRCS tests: date of first and most recent patient visit, KSC or non-KSC test facility (if applicable), test date, reason, results, and outcome, including where these data were found.

Statistical Analysis

We used chi-square statistics to determine if sociodemographic and health care use differed among cases and controls. For social desirability, we used an ANOVA to see if response tendencies differed by mode of administration.

Validity Analysis

For each screening test (FOBT, SIG, and COL), we compared a participant's self-report to his/her combined medical record. Both self-reported screening behavior and actual screening behavior were defined in terms of compliance with 2007 ACS guidelines. We calculated time from the most recent exam to the survey completion date for both self-report and medical record. For each screening test, validity was evaluated with four summary measures: concordance, sensitivity, specificity, and report-to-records ratio. We calculated two-sided 95% confidence intervals for all four measures. Estimates were calculated for each CRCS test across all modes of administration as well as stratified by mode of administration. We used Tisnado et al.'s (2006) criteria, where concordance, sensitivity, and specificity values > 0.9 indicated excellent agreement between a patient's self-report and the medical record and values > 0.8 indicated good agreement. Very few published studies of validity report CIs for sensitivity and specificity, and there are no published criteria for what is acceptable precision. We judged a measure to have good precision if the lower bound of the confidence limit was 0.80 or greater.

Reliability Analysis

We calculated the raw agreement between the initial and two-week surveys for receipt of each CRCS test within guidelines. We also calculated kappa statistics and 95% confidence intervals to correct for chance agreement. According to Landis and Koch (1977), kappa values between 0.61 and 0.79 indicate substantial agreement, and values greater than or equal to 0.80 indicate almost perfect agreement.

RESULTS

From September 2005 to December 2006, we invited 4,541 potential study candidates. We contacted 3,028 (67%), and the remaining 1,513 (33%) were not contacted because they could not be reached within the call limit (*n* = 370), had invalid contact information (*n* = 103), were deceased (*n* = 18), or were not needed because we had filled our sample (*n* = 1,022). Of the 3,028 we contacted, we lost 861 (28%) to follow-up either because they were unable to participate due to illness (*n* = 70) or were ineligible (*n* = 791). Of the remaining contacted (*n* = 2,167), 870 (40%) were enrolled, 99 (5%) dropped out after enrollment, and 1,198 (55%) refused.

As of January 26, 2007, we had completed data collection with 586 of the 870 enrollees. The case-control distribution was 201 controls (e.g., never or no recent CRCS test), 254 cases with a single CRCS test within guidelines, and 131 cases with multiple CRCS tests within guidelines.

There were no significant sociodemographic differences between cases and controls except for marital status (78% of cases were married compared with 70% of controls). The majority of cases and controls were less than 65 years old, female, non-Hispanic, Caucasian, and had some college or a college degree. Almost all cases and controls had visited a physician in the past year (96% and 92%, respectively), and all had visited a physician in the past two years. Cases were significantly more likely than controls to report physician recommendation of FOBT (50% vs. 22%) and SIG (82% vs. 48%) but not COL (56% vs. 53%). Average scores for the Marlowe-Crowne social desirability scale were significantly higher for respondents completing the face-to-face survey (mean = 6.08, SD = 1.48) compared with the mail survey (mean = 5.59, SD = 1.48). Scores for the telephone survey were intermediate (mean = 5.77, SD = 1.49).[Note]

Validity

Overall concordance estimates for FOBT, SIG, and COL self-reports met our criteria for good agreement—the concordance estimate was ≥ 0.80, and the lower confidence limit did not fall below 0.80 (Table 1). Estimates of concordance by mode of administration showed no significant mode differences within each CRCS test type—i.e., the CIs overlapped; however, the lower bound of the CI was below 0.80 for about half of the estimates.

Table 1a. Measure of Agreement (Concordance) between Self-Reports & the Combined Medical Record, by CRCS Test Type & Mode of Survey Administration for Patients Attending a Primary Care Clinic in Houston, Texas (*n* = 586)

		FOBT[Note]			**SIG**[Note]			**COL**[Note]	
Mode	***n***	**Concordance**	**95% CI**	***n***	**Concordance**	**95% CI**	***n***	**Concordance**	**95% CI**
Overall	586	0.84	(0.81–0.88)	586	0.84	(0.81–0.87)	586	0.88	(0.86–0.91)
Mail	197	0.84	(0.78–0.89)	197	0.85	(0.80–0.91)	197	0.89	(0.84–0.93)
Telephone	207	0.85	(0.80–0.90)	207	0.85	(0.79–0.90)	207	0.88	(0.84–0.93)
Face-to-face	182	0.84	(0.78–0.90)	182	0.82	(0.76–0.89)	182	0.88	(0.83–0.93)

[Note] Compliance with guidelines is defined as an annual FOBT or a SIG or COL within five years.

Table 1b. Measure of Agreement (Sensitivity) between Self-Reports & the Combined Medical Record, by CRCS Test Type & Mode of Survey Administration for Patients Attending a Primary Care Clinic in Houston, Texas (*n* = 586)

	FOBT[Note]			SIG[Note]			COL[Note]		
Mode	***n***	**Sensitivity**	**95% CI**	***n***	**Sensitivity**	**95% CI**	***n***	**Sensitivity**	**95% CI**
Overall	134	0.81	(0.74–0.89)	183	0.77	(0.70–0.84)	139	0.91	(0.86–0.96)
Mail	44	0.73	(0.57–0.88)	62	0.77	(0.66–0.89)	43	0.95	(0.89–1.00)
Telephone	61	0.87	(0.78–0.96)	57	0.75	(0.64–0.88)	56	0.89	(0.81–0.98)
Face-to-face	29	0.83	(0.68–0.98)	64	0.78	(0.67–0.90)	40	0.90	(0.80–1.00)

[Note] Compliance with guidelines is defined as an annual FOBT or a SIG or COL within five years.

Table 1c. Measure of Agreement (Specificity) between Self-Reports & the Combined Medical Record, by CRCS Test Type & Mode of Survey Administration for Patients Attending a Primary Care Clinic in Houston, Texas (*n* = 586)

	FOBT[Note]			SIG[Note]			COL[Note]		
Mode	***n***	**Specificity**	**95% CI**	***n***	**Specificity**	**95% CI**	***n***	**Specificity**	**95% CI**
Overall	452	0.85	(0.82–0.89)	403	0.87	(0.84–0.91)	447	0.87	(0.84–0.91)
Mail	153	0.87	(0.81–0.93)	135	0.89	(0.83–0.95)	154	0.87	(0.81–0.93)
Telephone	146	0.84	(0.78–0.91)	150	0.88	(0.82–0.94)	151	0.88	(0.83–0.94)
Face-to-face	153	0.84	(0.78–0.91)	118	0.85	(0.78–0.92)	142	0.87	(0.81–0.93)

[Note] Compliance with guidelines is defined as an annual FOBT or a SIG or COL within five years.

Table 1d. Measure of Agreement (Report-to-Records Ratio) between Self-Reports & the Combined Medical Record, by CRCS Test Type & Mode of Survey Administration for Patients Attending a Primary Care Clinic in Houston, Texas (*n* = 586)

	FOBT[Note 1]		SIG[Note 1]		COL[Note 1]	
Mode	**Report to Records Ratio**[Note 2]	**95% CI**	**Report to Records Ratio**[Note 2]	**95% CI**	**Report to Records Ratio**[Note 2]	**95% CI**
Overall	1.31	(1.15–1.47)	1.05	(0.94–1.16)	1.32	(1.18–1.45)
Mail	1.18	(0.91–1.46)	1.02	(0.84–1.19)	1.42	(1.16–1.68)
Telephone	1.25	(1.04–1.45)	1.07	(0.87–1.27)	1.21	(1.02–1.40)
Face-to-face	1.66	(1.18–2.13)	1.06	(0.88–1.24)	1.35	(1.08–1.62)

[Note 1] Compliance with guidelines is defined as an annual FOBT or a SIG or COL within five years.

[Note 2] Report-to-records ratio is a measure of net bias in test reporting with values greater than 1.0 indicating overreporting and values less than 1.0 indicating underreporting.

The overall sensitivity estimate for COL was good, but estimates for FOBT and SIG did not meet the criterion that the lower bound of the CI be at least 0.80, and for SIG, the point estimate was below 0.80 (Table 1). Sensitivity estimates also varied by mode of administration. For FOBT, the sensitivity estimate for respondents completing the mailed survey was less than 0.80 and was lower compared with those completing telephone and face-to-face interviews, although the CIs overlapped (Table 1). The reverse was true for COL self-reports, where sensitivity was higher for mail respondents, although, again, the CIs overlapped. There was no apparent difference by mode for SIG self-reports. The CIs for all of the sensitivity estimates were wider than those for concordance and specificity.

Overall estimates of specificity met our criteria for acceptability (Table 1). All specificity estimates by mode of administration also were greater than 0.80; however, for SIG and FOBT, the lower bound of the CI was slightly below 0.80.

The overall report-to-records ratios indicated overreporting for FOBT and COL but not for SIG (Table). These patterns were consistent across mode for each of the tests although the CIs were wide.

Reliability

The raw agreement between the initial and two-week reliability surveys was over 87% for FOBT, 89% for SIG, and 95% for COL. Kappa statistics for FOBT (k = 0.71, 95% CI: 0.70–0.73) and SIG (k = 0.73, 95% CI: 0.72–0.74) indicated substantial agreement between initial and second surveys based on Landis and Koch's (1977) criteria. For COL, the agreement was almost perfect (k = 0.89, 95% CI: 0.88–0.91).

DISCUSSION

Our findings compare favorably with past validity studies that assessed recent FOBT, SIG, and COL self-reports. The NCI CRCS questionnaire items assessing recency of FOBT, SIG, and COL achieved acceptable levels of concordance, specificity, and two-week test-retest reliability. General levels of raw agreement for each CRCS test type with the medical record were above 80%, and patients were able to accurately recall not having a particular CRCS test. We could not directly compare our test-retest reliability with Bradbury et al.'s findings (2005) because we used different prevalence definitions (e.g., FOBT in the past year vs. ever had FOBT) and different time intervals between surveys (e.g., Bradbury and colleagues' mean time interval was 77 days).

The sensitivity estimate for recent COL was good to excellent, with 91% of respondents accurately recalling having had the test, while sensitivity estimates for questions about the most recent FOBT and SIG were not as good, probably due to small numbers. In other words, patients had a harder time recalling whether they had had an FOBT in the past year or a SIG in the past five years.

The differences in recall across CRCS test types may be due to test characteristics. Some researchers have suggested that COL may be more memorable to patients because they were sedated, needed to arrange for transport from the procedure, and needed to take a full day off from work. For SIG, in particular, patients may be confusing this test type with COL. In other words, people may not recall the name of the test and falsely label it a COL. COL has received more attention from the media, and so it may have more name recognition. Alternatively, patients may believe COL is a superior screening test and, therefore, may want to recall that they had the "better" test (Meissner, Breen, Klabunde, & Vernon, 2006). This finding may also account for the higher report-to-records ratio—i.e., overreporting—found for COL. For FOBT, a possible reason for lower sensitivity may be recall bias with respect to time period. Patients may recall receipt of an FOBT as happening more recently than it did. We are currently investigating whether a 15-month time window increases sensitivity; however, Tisnado et al.'s (2006) findings suggest that variations in the time window do not substantially alter concordance.

Our response rate of 40% may introduce response bias, but the direction and magnitude of any potential bias is unclear. Recent methodological research suggests that lower response rates do not necessarily indicate larger biases in survey estimates (Keeter, Miller, Kohut, Groves, & Presser, 2000; Tourangeau, 2004). Another potential limitation of our study is that the findings may not generalize to other health care settings, such as community clinics. We chose to conduct the study in a clinic setting with a relatively stable patient population where the medical records and administrative data sources were likely to be accurate and complete. Thus, our estimates probably represent a "best case" scenario.

Conclusion

Valid and reliable self-report measures are a critical component of CRC prevention and control research. This study provides empirical support for the use of the NCI CRCS questionnaire to assess prevalence of recent behavior. Intervention researchers using the questionnaire to assess CRCS prevalence should weigh their selection of mode of administration against their research objectives (i.e., whether it is more important to reduce false positives or false negatives) and the characteristics of their target population. Future research should investigate the performance of the NCI CRCS questionnaire in different health care settings.

REFERENCES

American Cancer Society. (2007). *Cancer facts and figures, 2007.* Atlanta: Author.

Baier, M., Calonge, B. N., Cutter, G. R., McClatchey, M. W., Schoentgen, S., Hines, S., et al. (2000). Validity of self-reported colorectal cancer screening behavior. *Cancer Epidemiology, Biomarkers & Prevention, 9,* 229–232.>

Bastani, R., Gallardo, N. V., & Maxwell, A. E. (2001). Barriers to colorectal cancer screening among ethnically diverse high- and average-risk individuals. *Journal of Psychosocial Oncology, 19,* 65–84.>

Beeker, C., Kraft, J. M., Southwell, B. G., & Jorgensen, C. M. (2000). Colorectal cancer screening in older men and women: Qualitative research findings and implications for intervention. *Journal of Community Health, 25,* 263–277.

Bradbury, B. D., Brooks, D. R., Brawarsky, P., & Mucci, L. A. (2005). Test-retest reliability of colorectal testing questions on the Massachusetts Behavioral Risk Factor Surveillance System (BRFSS). *Preventive Medicine, 41,* 303–311.

Dillman, D. A. (1978). *Mail and telephone surveys: The total design method*. New York: John Wiley & Sons.

Fiscella, K., Holt, K., Meldrum, S., & Franks, P. (2006). Disparities in preventive procedures: Comparisons of self-report and Medicare claims data. *BioMed Central Health Services Research, 6,* 1–8.

Goel, V., Gray, R. E., Chart, P. L., Fitch, M., Saibil, F., & Zdanowicz, Y. (2004). Perspectives on colorectal cancer screening: A focus group study. *Health Expectations, 7,* 51–60.

Hiatt, R. A., Klabunde, C. N., Breen, N. L., Swan, J., & Ballard-Barbash, R. (2002). Cancer screening practices from National Health Interview Surveys: Past, present, and future. *Journal of the National Cancer Institute, 94,* 1837–1846.

Keeter, S., Miller, C., Kohut, A., Groves, R. M., & Presser, S. (2000). Consequences of reducing nonresponse in a national telephone suvey. *Public Opinion Quarterly, 64,* 125–148.

Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics, 33,* 159–174.

Madlensky, L., McLaughlin, J. R., & Goel, V. (2003). A comparison of self-reported colorectal cancer screening with medical records. *Cancer Epidemiology, Biomarkers & Prevention, 12,* 656–659.

Meissner, H. I., Breen, N. L., Klabunde, C. N., & Vernon, S. W. (2006). Patterns of colorectal cancer screening uptake among men and women in the US. *Cancer Epidemiology, Biomarkers & Prevention, 15,* 389–394.

Peabody, J. W., Luck, J., Glassman, P., Dresselhaus, T. R., & Lee, M. (2000). Comparison of vignettes, standardized patients, and chart abstraction: A prospective validation study of 3 methods for measuring quality. *Journal of the American Medical Association, 283,* 1715–1722.

Strahan, R., & Gerbasi, K. C. (1972). Short, homogeneous versions of the Marlowe-Crowne Social Desirability Scale. *Journal of Clinical Psychology, 28,* 191–193.

Tisnado, D. M., Adams, J. L., Liu, H., Damberg, C. L., Chen, W.-P., Hu, F. A., et al. (2006). What is the concordance between the medical record and patient self-report as data sources for ambulatory care? *Medical Care, 44,* 132–140.

Tourangeau, R. (2004). Survey research and societal change. *Annual Review of Psychology, 55,* 775–801.

Vernon, S. W., Briss, P. A., Tiro, J. A., & Warnecke, R. B. (2004). Some methodologic lessons learned from cancer screening research. *Cancer, 101,* 1131–1145.

Vernon, S. W., Meissner, H. I., Klabunde, C. N., Rimer, B. K., Ahnen, D., Bastani, R., et al. (2004). Measures for ascertaining use of colorectal cancer screening in behavioral, health services, and epidemiologic research. *Cancer Epidemiology, Biomarkers & Prevention, 13,* 898–905.

Weitzman, E. R., Zapka, J. G., Estabrook, B., & Goins, K. V. (2001). Risk and reluctance: Understanding impediments to colorectal screening. *Preventive Medicine, 32,* 502–513.

[Note] ANOVA results: $F(2, 583) = 5.22$, $p = 0.0057$.

FEATURE PAPER: Reliability and Data Quality in the National Survey on Drug Use and Health

Joel Kennet, Joe Gfroerer, and Peggy Barker, *Substance Abuse and Mental Health Services Administration*
Lanny Piper, Erica Hirsch, Becky Granger, and James R. Chromy, *RTI International*

INTRODUCTION

Information on data quality should be a standard output of major federal surveys, as these data can influence major policy decisions. Most surveys dutifully report on response rates and sampling error, but not on measurement error. Response rates, which can indicate potential sources of bias in data, cannot truly measure data accuracy. Re-interviewing respondents provides a direct measure of response variance. In other words, the capability of the survey to provide accurate data and consequent population estimates can be determined by assessing its reliability. Reliability is of particular concern when respondents are asked questions on sensitive topics. In addition, when particular population subgroups yield different estimates of reliability, concerns may be raised regarding the cultural competency of the survey instrument and the validity of conclusions about health disparities (Johnson & Bowman, 2003).

A few surveys on substance use have carried out test-retest reliability studies in the past and have reported differential response consistency across racial groups (Shea, Stein, Lantigua, & Basch, 1991; Stein, Lederman, & Shea, 1993; Stein, Courval, Lederman, & Shea, 1995; Johnson & Mott, 2001). With the exception of the Johnson and Mott study, these have been carried out on state and local samples or have had other limitations with respect to their ability to produce generalizable results. While conducted on a national sample (NLSY), the Johnson and Mott study produced results that were contradicted in another study using more recent waves of data (Shillington & Clapp, 2000). An additional consideration is that none of the surveys analyzed for reliability used audio computer-assisted self-interview (ACASI) administration, which seems likely to enhance response consistency.

The National Survey on Drug Use and Health (NSDUH) is an annual cross-sectional household survey of the civilian, noninstitutionalized U.S. population age 12 and older. The survey gathers data on the recency and frequency of use of alcohol, tobacco, and illicit substances from a probability sample of approximately 67,500 respondents selected each year in all 50 states and the District of Columbia. Recognizing that illicit drug use is a sensitive topic, the NSDUH uses state-of-the-art methods to assure respondents of their privacy and confidentiality in providing truthful data. The majority of the survey is administered in ACASI mode so that no persons other than respondents are able to see the answers provided. Further, NSDUH staff have taken many steps to assure that the questionnaire and other survey instruments are understandable to a broad cross-section of the population. New items undergo extensive expert review and cognitive testing, and the full questionnaire receives periodic reviews for readability. While several studies have been done to assess the validity of self-reported drug use in NSDUH, its test-retest reliability has never been studied before.

In an effort to assess the reliability of NSDUH data, a study was carried out during April–December 2006, wherein a subset of respondents participated in a reliability study. We refer to reliability as the extent to which respondents answered alike when the same questions were presented on two occasions separated by a specified time period.

High reliability is a necessary condition that must be met for data to be considered valid. If a question or set of questions proves unreliable, either within a particular population subgroup or overall, then discussion of disparities in the construct purportedly being measured loses its grounding. For example, if the overall reliability of the NSDUH measure of depression was found to be good but its reliability among a specific subpopulation was poor, then any disparity in depression prevalence between the specific subpopulation and others might simply be an artifact resulting from measurement error.

At the time of this writing, reliability study data obtained in the fourth quarter of 2006 are being cleaned and processed for inclusion in the final data set. Therefore, this paper will describe only results obtained using the responses from the second and third quarters of 2006. Results from the full reliability study are expected to become available in late 2007. Data from approximately 2,200 NSDUH respondents are included in the present analyses. The full data set will contain approximately 3,100 paired interview records. When analyses are complete, it is expected that the study will reveal which NSDUH measures are most at risk of producing unreliable estimates, and which population subgroups might tend to produce reliability scores that differ from others.

METHODS

Participants

The reliability study sample was drawn from the NSDUH main sample. For practical reasons, respondents in Alaska and Hawaii were not included in the reliability study, nor were non-English speaking respondents in any state, although Spanish-speaking respondents are included in the main sample. In addition, as a precaution against contamination of the data, the reliability study did not include respondents in households in which more than one person was selected to participate in the survey. Table 1 shows the demographic characteristics of the sample based on the first interview.

Table 1. Sample Composition

CHARACTERISTIC	*N*
TOTAL	2,204
Age	
12–17	695
18–25	684
26 or older	825
Race/Ethnicity	
White, not Hispanic	1,511
Black, not Hispanic	312
Other, not Hispanic	148
Hispanic	225
Gender	
Male	994
Female	1,210
Family Income	
$24,999 or less	550
$25,000–$49,999	617
$50,000–$74,999	326
$75,000–$99,999	207
$100,000 or more	253
Country of Birth	
U.S. born	2,068
Foreign born	136
County Type	
Metropolitan	1,783
Nonmetropolitan	421
Health Insurance	
Covered	1,849
Not covered	342
Education	
Less than high school	102
High school diploma	251
Some college	214
College graduate	258

Source: SAMHSA, Office of Applied Studies, National Survey on Drug Use and Health, Q2 & Q3 of 2006.

Materials & Procedure

The materials and procedures used in the reliability study were nearly identical to those used in the 2006 NSDUH main study (for detailed descriptions see SAMHSA, 2005, and the Methodological Resource Book on the SAMHSA Web site). To summarize, potential respondent households received a letter that briefly described the survey and encouraged participation. Interviewers arrived at these households within several days and attempted to administer the screener using a hand-held computer. After being selected and agreeing to participate, respondents answered a few demographic questions verbally and then began the ACASI portion of the survey. Interviews were administered as privately as was practical, and headphones were used to assure privacy. After completing the ACASI section, the interviewer retrieved the computer and asked a series of demographic questions, which were read aloud by the interviewer from the computer screen. Finally, the interviewer thanked the respondent and paid a $30 incentive. At this point, if a respondent was selected for the reliability study, additional screens would appear on the laptop, which the interviewer would read in an attempt to recruit the respondent for an additional study, the purpose of which was to "help us improve our interviewing procedures and how we ask questions." Neither respondents nor interviewers were aware beforehand that there would be an opportunity for a second interview. A $50 incentive was offered for the re-interview, which was scheduled to be administered 5–15 days later. An additional manipulation was whether the same interviewer or a different one would return for the second interview. The analyses in this paper will report on data pooled over these two conditions.

Demographic Variables

Demographic variables used in the tables are based on the first interview conducted with each respondent. No effort was made to resolve any differences with the re-interview demographic classifications or to assess their reliability. For the purposes of this paper, they are used simply to define subpopulation groups of interest for the evaluation of reliability of the outcome variables discussed below.

Outcome Variables

Lifetime Substance Use

The NSDUH ACASI section asks about respondents' experiences with a wide variety of illicit drugs, alcohol, and tobacco. This analysis is limited to use of cigarettes, alcohol, marijuana, and nonmedical use of prescription drugs. Similar to other preliminary analyses in NSDUH done using raw substance use variables, respondents with missing data for a particular substance were considered not to have used that substance.

Past-Year Substance Use

Positive responders to the lifetime substance use questions are routed into past-year and past 30-day questions for each substance indicated. For the sake of comparisons, the same four categories of drugs were chosen for this analysis.

Past-Year Health Conditions

Substance dependence or abuse. These constructs are measured using a series of questions based on DSM-IV criteria that ask about past-year behaviors and mental states resulting from use of specific substances. They are scored additively, with a cut-off point determining final classification. Similar to the substance use measures, the substance dependence or abuse variables were created so that missing responses were categorized as not having dependence or abuse.

*Depression.*The NSDUH asks a series of questions to determine whether respondents have had a major depressive episode (MDE) in their lifetime and, if so, whether one occurred within the past 12 months. For brevity, we report only on the past 12 months. Youths and adults receive slightly different question sets, so responses were analyzed separately.

Serious psychological distress (SPD). This construct is measured with the K6 scale (Kessler et al., 2003), a series of six items in which adult respondents rate the frequency, on a five-point scale, with which they have experienced various negative emotional states during the worst month, emotionally, in the past year. The scale is scored additively, with a cutoff point determining final classification. Missing values were given a score of zero for each of the scale items.

High blood pressure. The NSDUH uses a health conditions checklist to obtain lifetime and past-year prevalences of a variety of conditions. For this study, we chose to report on past-year high blood pressure because of its relatively high prevalence and its importance in predicting other health outcomes.

Past-Year Health Care Utilization

Substance use treatment. Respondents who report prior use of any substance are routed to a question about lifetime receipt of substance use treatment; those who respond positively then are asked about receipt of substance use treatment in the past year. We report only on past-year treatment receipt in this paper.

Mental health treatment. Youths and adults receive different questions regarding receipt of mental health treatment in the previous 12 months. Thus, responses are analyzed separately. Respondents with missing values were considered not to have received treatment.

Health insurance. This is the only outcome variable used in this paper asked in the interviewer-administered section of the interview. Note that the reference period for this variable is current, although the NSDUH does contain questions asking whether respondents were not covered at any time in the past year. Also, proxy responses are included in the analysis.

Analytic Approach

Cohen's measure of inter-rater agreement (Cohen, 1960) was calculated for each outcome measure. Kappas then were calculated for each demographic subgroup. Tables were prepared so that kappas are displayed alongside prevalence estimates from 2005, which are assumed to approximate the as-yet unreleased 2006 estimates. Using the tables, we attempt to highlight instances where subgroup kappas appeared to differ from those of their complement in the sample, in the absence of major differences in prevalence rates. This additional step was taken because differences in kappas can occur even when reliability levels are similar if the true prevalence rates are different. The opposite also can occur with unequal prevalence across subgroups; subgroup kappas may be similar while differences in reliability may actually exist. Thus, the interpretation of kappa differences will be restricted to situations where differences in prevalence are not large.

RESULTS

Reliability of the measures chosen for this study is reported in the form of Cohen's kappas. For purely descriptive purposes, we consider kappas greater than .9 to indicate very good reliability, .8–.89 good, .7–.79 fair, .6–.69 modest, and .59 or below, poor. However, given the complexity of some of the measures reported and the intangible and transient nature of some of the constructs that the NSDUH attempts to measure, one could argue for a less stringent set of criteria, as Landis and Koch (1977) and others have done. These cutoffs were chosen simply for convenience. When calculating the kappas, respondents with missing data on the analytic variable at either the first interview or the re-interview were excluded. Note that analytic variables such as substance use, substance dependence or abuse, substance treatment, and serious psychological distress do not have any missing values due to the way they were recoded for analysis.

Lifetime Substance Use

Table 2 shows the overall and subgroup kappas obtained for these four measures. In general, these questions yielded good (kappa > .80) overall reliability. Few subgroup differences in kappa appeared in the absence of differences in prevalence. However, persons in the $75,000–$99,999 income range did appear to be more consistent than others in reporting lifetime cigarette and marijuana use.

Table 2a. Lifetime Substance Use: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Age

Nonmedical Use of

	Cigarettes		Alcohol		Marijuana		Prescription Drugs	
Age	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	66.6	.88	82.9	.83	4.1	.94	2.0	.82
12–17	26.7	.90	4.6	.79	17.4	.91	11.9	.57
18–25	67.3	.96	85.7	.81	52.4	.93	3.3	.86
26 or older	71.9	.85	88.2	.80	41.1	.94	19.3	.83

NOTE: Age group is based on raw data from the Time 1 interview.
Source: SAMHSA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 2b. Lifetime Substance Use: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Hispanic Origin & Race

	Cigarettes		Alcohol		Marijuana		Nonmedical Use of Prescription Drugs	
Hispanic Origin and Race	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	66.6	.88	82.9	.83	4.1	.94	2.0	.82
White, not Hispanic	72.2	.90	86.9	.85	43.7	.95	22.3	.81
Black, not Hispanic	55.7	.89	75.2	.80	39.0	.89	12.6	.62
Other, not Hispanic	48.3	.82	67.9	.78	26.3	.97	16.0	.86
Hispanic or Latino	55.3	.84	75.6	.81	28.8	.90	16.6	.88

NOTE: Race/ethnicity is based on raw data from the Time 1 interview.
Source: SAMHSA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 2c. Lifetime Substance Use: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Gender

	Cigarettes		Alcohol		Marijuana		Nonmedical Use of Prescription Drugs	
Gender	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	66.6	.88	82.9	.83	4.1	.94	2.0	.82
Male	71.3	.89	86.3	.83	45.0	.93	21.9	.79
Female	62.1	.88	79.8	.83	35.5	.95	18.3	.85

NOTE: Gender is based on raw data from the Time 1 interview.
Source: SAMHSA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 2d. Lifetime Substance Use: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Family Income

	Cigarettes		Alcohol		Marijuana		Nonmedical Use of Prescription Drugs	
Family Income	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	66.6	.88	82.9	.83	4.1	.94	2.0	.82
Less than $25,000	62.5	.86	73.9	.77	35.8	.90	2.5	.81
$25,000–$49,999	66.8	.83	82.4	.85	36.5	.94	19.3	.83
$50,000–$74,999	69.6	.86	86.4	.77	42.7	.94	2.0	.83
$75,000–$99,999	68.2	.98	87.1	.92	45.0	.98	2.8	.79
$100,000 or more	66.2	.91	87.7	.85	46.2	.96	2.4	.89

NOTE: Family income is based on raw data from the Time 1 interview.
Source: SAMHSA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 2e. Lifetime Substance Use: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Country of Birth

	Cigarettes		Alcohol		Marijuana		Nonmedical Use of Prescription Drugs	
Country of Birth	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	66.6	.88	82.9	.83	4.1	.94	2.0	.82
United States	69.5	.88	84.8	.85	43.6	.94	21.3	.82
Other	48.8	.88	71.9	.68	19.4	.91	12.4	.76

NOTE: Country of birth is based on raw data from the Time 1 interview.
Source: SAMHSA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 2f. Lifetime Substance Use: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by County Type

	Cigarettes		Alcohol		Marijuana		Nonmedical Use of Prescription Drugs	

County Type	2005 %	Kappa	2005 %	Kappa	2005 %	Kappa	2005 %	Kappa
TOTAL	66.6	.88	82.9	.83	4.1	.94	2.0	.82
Metropolitan	65.8	.90	83.1	.83	4.8	.94	2.3	.83
Nonmetropolitan	7.5	.82	81.9	.85	36.8	.94	18.6	.70

NOTE: County type is based on raw data from the Time 1 interview.
Source: SAMHSA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 2g. Lifetime Substance Use: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Health Insurance

	Cigarettes		Alcohol		Marijuana		Nonmedical Use of Prescription Drugs	
Health Insurance	2005 %	Kappa	2005 %	Kappa	2005 %	Kappa	2005 %	Kappa
TOTAL	66.6	.88	82.9	.83	4.1	.94	2.0	.82
Currently covered	66.2	.89	83.1	.84	38.8	.94	18.8	.81
Not currently covered	68.7	.82	81.9	.75	48.1	.92	27.7	.83

NOTE: Health insurance is based on raw data from the Time 1 interview.
Source: SAMHSA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 2h. Lifetime Substance Use: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Education[1]

	Cigarettes		Alcohol		Marijuana		Nonmedical Use of Prescription Drugs	
Education	2005 %	Kappa	2005 %	Kappa	2005 %	Kappa	2005 %	Kappa
TOTAL	66.6	.88	82.9	.83	4.1	.94	2.0	.82
< High school	64.9	.85	74.8	.64	27.4	.89	15.3	.77
High school graduate	72.7	.80	87.3	.84	39.1	.94	18.3	.78
Some college	75.9	.84	92.5	.83	47.0	.95	22.4	.85
College graduate	71.3	.91	92.8	.86	45.5	.94	2.1	.86

NOTE: Education is based on raw data from the Time 1 interview.
[1] Education is only among respondents age 26 or older.
Source: SAMHSA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Past-Year Substance Use

Table 3 contains the overall and subgroup kappas obtained for the past-year substance use measures. Like the lifetime measures, these yielded mostly good kappas overall, the exception being nonmedical use of prescription drugs, for which kappa was calculated at .67.

Subgroup differences appear to be present by race/ethnicity, education, and income. Among the four race categories, Whites appeared more consistent than their complement in reporting past-year cigarette and marijuana use. Blacks appeared less and Hispanics more consistent in reporting past-year marijuana use than their respective complements in the sample. For income, the sole kappa difference unlikely to be attributed to prevalence differences was in nonmedical use of prescription drugs: the $100,000+ group appeared to be more consistent than the groups with lower income levels. Finally, education seemed to have mixed effects. Persons with less than a high school education appeared less reliable than others in reporting past-year marijuana use but more reliable in reporting nonmedical use of prescription drugs. College graduates appeared more consistent than others in reporting past-year marijuana use.

Table 3a. Past-Year Substance Use: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Age

	Cigarettes		Alcohol		Marijuana		Nonmedical Use of Prescription Drugs	
Age	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	29.1	.91	66.5	.87	1.4	.85	6.2	.67
12–17	17.3	.86	33.3	.70	13.3	.80	8.3	.37
18–25	47.2	.92	77.9	.81	28.0	.92	15.0	.72
26 or older	27.6	.90	69.0	.88	6.9	.81	4.4	.69

NOTE: Age group is based on raw data from the Time 1 interview.
Source: SAMHSA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 3b. Past-Year Substance Use: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Hispanic Origin & Race

	Cigarettes		Alcohol		Marijuana		Nonmedical Use of Prescription Drugs	
Hispanic Origin & Race	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	29.1	.91	66.5	.87	1.4	.85	6.2	.67
White, not Hispanic	3.1	.94	7.5	.90	1.6	.90	6.8	.72
Black, not Hispanic	27.4	.88	55.5	.84	12.3	.55	4.1	.39
Other, not Hispanic	23.5	.80	54.8	.84	7.4	.67	4.2	.63
Hispanic or Latino	27.9	.81	6.6	.76	9.1	.96	6.3	.58

NOTE: Race/ethnicity is based on raw data from the Time 1 interview.
Source: SAMHSA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 3c. Past-Year Substance Use: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Gender

	Cigarettes		Alcohol		Marijuana		Nonmedical Use of Prescription Drugs	
Gender	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	29.1	.91	66.5	.87	1.4	.85	6.2	.67
Male	31.9	.91	7.3	.86	13.1	.85	6.6	.70
Female	26.5	.90	62.8	.88	7.9	.84	5.9	.62

NOTE: Gender is based on raw data from the Time 1 interview.
Source: SAMHSA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 3d. Past-Year Substance Use: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Family Income

	Cigarettes		Alcohol		Marijuana		Nonmedical Use of Prescription Drugs	
Family Income	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	29.1	.91	66.5	.87	1.4	.85	6.2	.67
Less than $25,000	37.5	.95	52.9	.87	13.9	.78	8.3	.64
$25,000–$49,999	32.3	.85	63.4	.90	1.8	.88	6.4	.61
$50,000–$74,999	26.8	.96	7.8	.82	8.9	.82	5.6	.67
$75,000–$99,999	23.8	.98	74.4	.95	8.6	.89	4.5	.71
$100,000 or more	19.0	.89	78.1	.88	8.7	.91	5.5	.89

NOTE: Family income is based on raw data from the Time 1 interview.
Source: SAMHSA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 3e. Past-Year Substance Use: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Country of Birth

	Cigarettes		Alcohol		Marijuana		Nonmedical Use of Prescription Drugs	
Country of Birth	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	29.1	.91	66.5	.87	1.4	.85	6.2	.67
United States	3.4	.92	68.0	.89	11.5	.85	6.7	.69
Other	21.3	.79	57.0	.71	4.3	.90	3.7	.26

NOTE: Country of birth is based on raw data from the Time 1 interview.
Source: SAMHSA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 3f. Past-Year Substance Use: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by County Type

	Cigarettes		Alcohol		Marijuana		Nonmedical Use of Prescription Drugs	
County Type	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	29.1	.91	66.5	.87	1.4	.85	6.2	.67
Metropolitan	28.3	.90	68.0	.87	1.8	.84	6.3	.68
Nonmetropolitan	33.2	.93	58.9	.85	8.4	.89	6.1	.62

NOTE: County type is based on raw data from the Time 1 interview.
Source: SAMHSA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 3g. Past-Year Substance Use: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Health Insurance

	Cigarettes		Alcohol		Marijuana		Nonmedical Use of Prescription Drugs	
Health Insurance	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	29.1	.91	66.5	.87	1.4	.85	6.2	.67
Currently covered	26.4	.89	66.5	.87	9.2	.87	5.5	.68
Not currently covered	46.2	.96	66.4	.84	18.1	.76	1.7	.61

NOTE: Health insurance is based on raw data from the Time 1 interview.
Source: SAMHSA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 3h. Past-Year Substance Use: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Education[1]

	Cigarettes		Alcohol		Marijuana		Nonmedical Use of Prescription Drugs	
Education	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	29.1	.91	66.5	.87	1.4	.85	6.2	.67
< High school	35.4	.86	48.5	.90	7.4	.60	5.2	.99
High school graduate	32.6	.88	64.6	.85	7.4	.81	4.2	.72
Some college	29.5	.91	75.0	.88	7.2	.78	4.8	.59
College graduate	16.5	.97	79.5	.89	6.0	.97	3.9	.52

NOTE: Education is based on raw data from the Time 1 interview.
[1] Education is only among respondents age 26 or older.
Source: SAMHSA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Past-Year Health Conditions

Table 4 shows the overall and subgroup kappas obtained on the health condition measures. Overall, kappas for these measures ranged from .49–.70, indicating poor to fair reliability, at least in comparison with the other measures in this analysis. Within the individual measures, there were some apparent differences in kappa related to race. Whites appeared more consistent than other groups in reporting dependence or abuse; Blacks appeared more consistent in reporting MDE for both youths and adults; Hispanics appeared less consistent in reporting dependence or abuse. The breakdown by education highlighted college graduates as potentially more consistent than others in reporting SPD and high blood pressure.

Past-Year Health Care Utilization

Table 5 depicts the kappas for the variables related to health care use. These kappas ranged from .57–.91, indicating a fairly wide range of reliability. White youths appeared more likely to provide consistent responses than other youths regarding receipt of mental health treatment. Family income level appeared to be related to reliability as well. Adults in the group with less than $25,000 income appeared to be less consistent than their complement in reporting receipt of mental health treatment, while those in the $25,000–$49,999 group appeared more consistent. College graduates appeared to be more consistent than other adults in reporting mental health treatment.

Table 4a. Past-Year Health Conditions: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Age

	Major Depressive Episode (Youth)		Major Depressive Episode (Adult)		Serious Psychological Distress (Adult)		Drug/Alcohol Dependence or Abuse		High Blood Pressure	
Age	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	8.8	.49	7.3	.66	11.3	.65	9.1	.56	15.7	.70
12–17	8.8	.49	—	—	—	—	8.0	.55	1.1	.70
18–25	—	—	9.7	.66	18.6	.72	21.8	.54	2.5	.77
26 or older	—	—	6.9	.66	1.0	.62	7.1	.56	19.9	.68

NOTE: Age group is based on raw data from the Time 1 interview.
Source: SAMSHA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 4b. Past-Year Health Conditions: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Hispanic Origin & Race

	Major Depressive Episode (Youth)		Major Depressive Episode (Adult)		Serious Psychological Distress (Adult)		Drug/Alcohol Dependence or Abuse		High Blood Pressure	
Hispanic Origin & Race	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	8.8	.49	7.3	.66	11.3	.65	9.1	.56	15.7	.70
White, not Hispanic	9.1	.46	7.6	.65	11.4	.69	9.4	.64	17.2	.67
Black, not Hispanic	7.6	—[1]	6.5	.94	1.7	.68	8.5	.65	18.8	.68
Other, not Hispanic	7.4	—[1]	5.7	—[1]	1.3	—[1]	7.4	.66	1.6	.88
Hispanic or Latino	9.1	—[1]	7.0	.39	11.7	.38	9.3	.19	7.5	.94

NOTE: Race/ethnicity is based on raw data from the Time 1 interview.
[1] Suppressed due to cell size less than 100.
Source: SAMSHA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 4c. Past-Year Health Conditions: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Gender

	Major Depressive Episode (Youth)		Major Depressive Episode (Adult)		Serious Psychological Distress (Adult)		Drug/Alcohol Dependence or Abuse		High Blood Pressure	
Gender	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	8.8	.49	7.3	.66	11.3	.65	9.1	.56	15.7	.70
Male	4.5	.52	5.2	.62	8.4	.68	12.0	.53	14.7	.73
Female	13.3	.47	9.3	.68	14.0	.62	6.4	.62	16.7	.67

NOTE: Gender is based on raw data from the Time 1 interview.
Source: SAMSHA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 4d. Past-Year Health Conditions: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Family Income

	Major Depressive Episode (Youth)		Major Depressive Episode (Adult)		Serious Psychological Distress (Adult)		Drug/Alcohol Dependence or Abuse		High Blood Pressure	
Family Income	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	8.8	.49	7.3	.66	11.3	.65	9.1	.56	15.7	.70
Less than $25,000	9.0	.43	11.4	.75	18.0	.67	11.7	.64	16.7	.60
$25,000–$49,999	9.2	.43	7.2	.66	11.2	.69	9.1	.60	16.6	.76
$50,000–$74,999	9.8	.70	6.7	.44	1.5	.43	7.6	.47	15.6	.68
$75,000–$99,999	8.1	—[1]	4.8	.94	7.2	.63	8.1	.72	14.0	.76
$100,000 or more	7.2	—[1]	5.1	.35	7.4	.62	8.7	.41	13.9	.71

NOTE: Family income is based on raw data from the Time 1 interview.

[1] Suppressed due to cell size less than 100.

Source: SAMSHA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 4e. Past-Year Health Conditions: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Country of Birth

	Major Depressive Episode (Youth)		Major Depressive Episode (Adult)		Serious Psychological Distress (Adult)		Drug/Alcohol Dependence or Abuse		High Blood Pressure	
Country of Birth	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	8.8	.49	7.3	.66	11.3	.65	9.1	.56	15.7	.70
United States	8.9	.50	7.7	.66	11.9	.64	9.6	.61	16.8	.68
Other	7.3	—[1]	4.8	.76	8.2	.80	6.1	.04	9.2	.93

NOTE: Country of birth isbased on raw data from the Time 1 interview.

[1] Suppressed due to cell size less than 100.

Source: SAMSHA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 4f. Past-Year Health Conditions: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by County Type

	Major Depressive Episode (Youth)		Major Depressive Episode (Adult)		Serious Psychological Distress (Adult)		Drug/Alcohol Dependence or Abuse		High Blood Pressure	
County Type	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	8.8	.49	7.3	.66	11.3	.65	9.1	.56	15.7	.70
Metropolitan	8.6	.49	7.2	.65	11.1	.64	9.3	.55	15.1	.70
Nonmetropolitan	9.7	.48	7.8	.75	12.4	.67	8.2	.66	18.9	.71

NOTE: County type is based on raw data from the Time 1 interview.

Source: SAMSHA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 4g. Past-Year Health Conditions: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Health Insurance

	Major Depressive Episode (Youth)		Major Depressive Episode (Adult)		Serious Psychological Distress (Adult		Drug/Alcohol Dependence or Abuse		High Blood Pressure	
Health Insurance	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	8.8	.49	7.3	.66	11.3	.65	9.1	.56	15.7	.70
Currently covered	8.8	.50	6.8	.64	1.6	.64	8.0	.54	17.0	.71
Not currently covered	9.2	—[1]	1.0	.74	15.4	.64	15.9	.63	7.7	.59

NOTE: Health insurance is based on raw data from the Time 1 interview.

[1] Suppressed due to cell size less than 100.

Source: SAMSHA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 4h. Past-Year Health Conditions: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Education[1]

	Major Depressive Episode (Youth)		Major Depressive Episode (Adult)		Serious Psychological Distress (Adult)		Drug/Alcohol Dependence or Abuse		High Blood Pressure	
Education	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	8.8	.49	7.3	.66	11.3	.65	9.1	.56	15.7	.70

< High school	—	—	7.0	.44	13.3	.78	7.6	.38	2.9	—[2]
High school graduate	—	—	6.4	.73	9.2	.56	6.7	.56	22.6	.65
Some college	—	—	8.0	.75	11.1	.52	7.2	.73	19.5	.59
College graduate	—	—	6.4	.47	8.2	.83	7.1	.52	16.8	.81

NOTE: Education is based on raw data from the Time 1 interview.

[1] Education is only among respondents age 26 and older.

[2] Suppressed due to cell size less than 100.

Source: SAMSHA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

DISCUSSION

This paper presents preliminary results from a reliability study carried out on the National Survey on Drug Use and Health. Over 3,100 respondents participated in the NSDUH Reliability Study, and this rich data set is likely to yield many important findings in the future.

Overall, the reliability of the measures chosen for this preliminary study ranged from kappa=.49–.91, depending on a variety of factors. Lifetime and past-year substance use measures performed relatively well, with kappas generally in the .8–.9 range. Health conditions and health care measures appeared somewhat less reliable, with kappas generally in the .5–.8 range. This difference may result from the fact that most of the health and health care measures were derived from sets of items rather than single ones. These measures also attempt to capture mental states and associated behaviors, as opposed to factual assertions of use or nonuse of specific substances. Thus, lower reliability for these measures was not surprising.

Table 5a. Past-Year Health Care Utilization: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Age

	Mental Health Treatment (Youth)		Mental Health Treatment (Adult)		Drug/Alcohol Treatment at Specialty Facility		Current Health Insurance	
Age	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	21.8	.57	13.0	.78	.9	.78	86.1	.91
12–17	21.8	.57	—	—	.7	.75	92.1	.88
18–25	—	—	11.2	.69	1.6	.60	72.4	.90
26 or older	—	—	13.3	.79	.9	.82	87.6	.92

NOTE: Age group is based on raw data from the Time 1 interview.

Source: SAMSHA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 5b. Past-Year Health Care Utilization: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Hispanic Origin & Race

	Mental Health Treatment (Youth)		Mental Health Treatment (Adult)		Drug/Alcohol Treatment at Specialty Facility		Current Health Insurance	
Hispanic Origin & Race	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	21.8	.57	13.0	.78	.9	.78	86.1	.91
White, not Hispanic	21.8	.68	15.1	.83	.8	.80	89.8	.94
Black, not Hispanic	24.2	—[1]	8.9	.67	1.8	.69	83.2	.72
Other, not Hispanic	18.9	—[1]	7.1	—[1]	.4	.0	87.0	1.00
Hispanic or Latino	2.7	.40	7.8	.46	1.2	1.0	68.8	.90

NOTE: Race/ethnicity is based on raw data from the Time 1 interview.

[1] Suppressed due to cell size less than 100.

Source: SAMSHA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 5c. Past-Year Health Care Utilization: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Gender

	Mental Health Treatment (Youth)		Mental Health Treatment (Adult)		Drug/Alcohol Treatment at Specialty Facility		Current Health Insurance	
Gender	2005 %	Kappa	2005 %	Kappa	2005 %	Kappa	2005 %	Kappa
TOTAL	21.8	.57	13.0	.78	.9	.78	86.1	.91
Male	2.0	.48	8.9	.86	1.3	.67	84.4	.89
Female	23.6	.63	16.8	.73	.6	.92	87.6	.94

NOTE: Gender is based on raw data from the Time 1 interview.
Source: SAMSHA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 5d. Past-Year Health Care Utilization: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Family Income

	Mental Health Treatment (Youth)		Mental Health Treatment (Adult)		Drug/Alcohol Treatment at Specialty Facility		Current Health Insurance	
Family Income	2005 %	Kappa	2005 %	Kappa	2005 %	Kappa	2005 %	Kappa
TOTAL	21.8	.57	13.0	.78	.9	.78	86.1	.91
Less than $25,000	25.3	.41	16.7	.47	2.1	.56	74.2	.91
$25,000–$49,999	22.2	.65	11.3	.90	.8	.92	81.3	.92
$50,000–$74,999	2.6	.65	13.4	.87	.6	.87	92.2	.84
$75,000–$99,999	2.8	—[1]	12.4	.84	.5	1.00	95.1	.91
$100,000 or more	19.5	—[1]	12.1	.86	.5	.98	96.7	1.00

NOTE: Family income is based on raw data from the Time 1 interview.

[1] Suppressed due to cell size less than 100.

Source: SAMSHA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 5e. Past-Year Health Care Utilization: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Country of Birth

	Mental Health Treatment (Youth)		Mental Health Treatment (Adult)		Drug/Alcohol Treatment at Specialty Facility		Current Health Insurance	
Country of Birth	2005 %	Kappa	2005 %	Kappa	2005 %	Kappa	2005 %	Kappa
TOTAL	21.8	.57	13.0	.78	.9	.78	86.1	.91
United States	22.1	.57	14.3	.79	1.1	.78	88.4	.91
Other	17.5	—[1]	5.4	.62	.3	—	71.9	.94

NOTE: Country of birth is based on raw data from the Time 1 interview.

[1] Suppressed due to cell size less than 100.

Source: SAMSHA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 5f. Past-Year Health Care Utilization: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by County Type

	Mental Health Treatment (Youth)		Mental Health Treatment (Adult)		Drug/Alcohol Treatment at Specialty Facility		Current Health Insurance	
County Type	2005 %	Kappa	2005 %	Kappa	2005 %	Kappa	2005 %	Kappa
TOTAL	21.8	.57	13.0	.78	.9	.78	86.1	.91
Metropolitan	21.8	.58	12.7	.79	.9	.79	86.2	.92
Nonmetropolitan	21.6	.52	14.4	.74	1.0	.64	85.3	.88

NOTE: County type is based on raw data from the Time 1 interview.
Source: SAMSHA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 5g. Past-Year Health Care Utilization: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Health Insurance

	Mental Health Treatment (Youth)		Mental Health Treatment (Adult)		Drug/Alcohol Treatment at Specialty Facility		Current Health Insurance	
Health Insurance	2005 %	Kappa	2005 %	Kappa	2005 %	Kappa	2005 %	Kappa
TOTAL	21.8	.57	13.0	.78	.9	.78	86.1	.91
Currently covered	22.1	.58	13.6	.79	.8	.77	—	—
Not currently covered	18.3	—	9.5	.68	1.9	.81	—	—

NOTE: Health insurance is bbased on raw data from the Time 1 interview.
Source: SAMSHA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

Table 5h. Past-Year Health Care Utilization: 2005 Prevalence Rates & Weighted Kappas from Q2 & Q3 of 2006, by Education[1]

	Mental Health Treatment (Youth)		Mental Health Treatment (Adult)		Drug/Alcohol Treatment at Specialty Facility		Current Health Insurance	
Education	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**	**2005 %**	**Kappa**
TOTAL	21.8	.57	13.0	.78	.9	.78	86.1	.91
< High school	—	—	11.0	.57	1.5	.80	74.4	.90
High school graduate	—	—	11.7	.79	.9	.79	86.4	.85
Some college	—	—	15.1	.71	.9	.68	88.9	.98
College graduate	—	—	14.6	.93	.5	1.00	94.9	.96

NOTE: Education is based on raw data from the Time 1 interview.
[1] Education is only among respondents age 26 and older.
Source: SAMSHA, Office of Applied Studies, National Survey on Drug Use and Health, 2005 and Q2 & Q3 of 2006.

The primary focus in this study was on possible differences in reliability among demographic subgroups. Data from over 2,200 reliability study respondents were used in this analysis. Our approach was to calculate Cohen's kappa for each subgroup and compare them with the kappas obtained by the complement of the sample. A problem with this approach is that Cohen's kappa is sensitive to prevalence; thus, it is possible to misattribute reliability differences when differences in prevalence are present. We therefore limited our interpretation to cases where kappas appeared to differ while prevalence was relatively constant across subgroups. Other approaches have been suggested. We expect to have determined the optimal statistical methodology by the time the full data set is available for analysis. Whatever the method, the important thing to determine is whether any meaningful patterns emerged in the findings and, if so, how they might translate into usable knowledge.

One pattern that seemed reasonably apparent was in the relation between age and response consistency. Not surprisingly, youths appeared less consistent (note the lower kappas for youths than those obtained for the complement) than young adults and older adults in their reporting of substance use, particularly in the cases of lifetime and past-year nonmedical prescription drug use and past-year alcohol use. Young adults and older adults had fewer kappas below those of the complement of the sample, and in a few cases, appeared more consistent than the other groups. However, as noted earlier, prevalence varies quite a bit by age, so the use of kappa to examine differences is somewhat limited.

Other patterns that appeared were related to race/ethnicity. White respondents appeared to be more consistent than others in reporting past-year substance use. If confirmed when more rigorous methods are applied, this finding should trigger further analyses to determine whether the survey instrument might be culturally slanted, Whites might feel less pressure to hide their substance use, or some other sociocultural factors might be active.

Recent interest in Hispanics' differential response patterns to questionnaire items about depression and mental health also can be addressed somewhat by these data. In the cases of major depressive episode, substance dependence/abuse, and serious psychological distress, the kappas attained by Hispanics appeared consistently lower than those attained by others. Findings from the full reliability study sample may be more telling and may lead to further investigation. However, because no reliability study interviews were conducted in Spanish, the equivalence of the NSDUH translations cannot be examined with these data.

A general pattern also appeared to be present in the case of income. Greater income was generally associated with greater response consistency. This result would only be surprising if educational level did not exhibit the same general pattern of association, which it did. These findings point toward efforts to lower the reading level of the instrument and to improve the comprehensibility of the supporting materials that describe the survey, the uses of the data, measures taken to enhance confidentiality, etc. In general, these findings might be seen as a reminder that practically all surveys are designed and conducted by persons with relatively high educational level and verbal skills, while respondents come from all strata within the population of interest. Keen awareness of that notion needs to be maintained during all stages of survey design, implementation, and analysis.

Persons attempting to analyze survey data on health disparities should be interested in the findings presented here. Consideration of the reliability of the survey instrument within the subgroups of interest is needed before concluding that the data indicate disparities. Apparent disparities may in fact be the result of failure to comprehend the instrument, words or concepts that do not translate well across groups, response options that fail to capture the full range of possibilities, and/or a host of other potential shortcomings of the measurement process. Cultural tendencies toward atypical response patterns, such as underreporting, also may be responsible.

Survey designers need to incorporate thorough pretesting of measures that are intended for administration to a diverse population. Focus groups, cognitive testing, expert reviews including experts on the subpopulations in question) and other methods have been devised as means of improving survey instrumentation, and they have been shown to produce quantifiable effects in reducing age-group related variability in response (e.g., Kennet, Painter, Barker, Aldworth, & Vorburger, 2005) and other improvements. Budgeting of time and money for instrument development often is neglected, while interest in the measurement of health disparities increases.

REFERENCES

Cohen, J. (1960). A coefficient of agreement for nominal scales. *Psychological Bulletin, 70,* 213–220.

Johnson, T. P., & Bowman, P. J. (2003). Cross-cultural sources of measurement error in substance use surveys. *Substance Use and Misuse, 38,* 1447–1490.

Johnson, T. P., & Mott, J. A. (2001). The reliability of self-reported age on onset of tobacco, alcohol and illicit drug use. *Addiction, 96,* 1187–1198.

Kennet, J., Painter, D., Barker, P., Aldworth, J., & Vorburger, M. (2005). Applying cognitive psychological principles to the improvement of survey data: A case study from the National Survey on Drug Use and Health. In *Proceedings of the Survey Research Methods Section of the American Statistical Association* (pp. 3887–3897). Alexandria, VA: American Statistical Association.

Kessler, R. J., Barker, P. R., Colpe, L. J., Epstein, J. F., Gfroerer, J. C., Hiripi, E., et al. (2003). Screening for serious mental illness in the general population. *Archives of General Psychiatry 60,* 184–189.

Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics, 33,* 159–174.

SAMHSA. (2005). *2006 National Survey on Drug Use and Health: Reliability study protocol.* Office of Applied Studies, Internal Report.

SAMHSA. (2007). *2006 NSDUH methodological resource book.* Office of Applied Studies. Retrieved May 30, 2007, from www.oas.samhsa.gov/ nsduh/methods.cfm#2k6

Shea, S., Stein, A. D., Lantigua, R., & Basch, C. E. (1991). Reliability of the Behavioral Risk Factor Survey in a triethnic population. *American Journal of Epidemiology, 133,* 489–500.

Shillington, A. M., & Clapp, J. P. (2000). Self-report stability of adolescent substance use: Are there differences for gender, ethnicity and age? *Drug and Alcohol Dependence, 60,* 19–27.

Stein, A. D., Lederman, R. I., & Shea, S. (1993). The Behavioral Risk Factor Surveillance System questionnaire: Its reliability in a statewide sample. *American Journal of Public Health, 83,* 1768–1772.

Stein, A. D., Courval, J. M., Lederman, R. I., & Shea, S. (1995). Reproducibility of responses to telephone interviews: Demographic predictor of discordance in risk factor status. *American Journal of Epidemiology, 141,* 1097–1106.

FEATURE PAPER: Disability: Collecting Self-Reports and Objective Measures from Seniors

Patricia Gallagher, *University of Massachusetts Boston*
Kate Stewart, *Harvard School of Public Health*
Carol Cosenza and Rebecca Crow, *University of Massachusetts Boston*

INTRODUCTION

To estimate disability in the elderly population, national longitudinal surveys of aging and health frequently include self-reported measures of ability to conduct activities of daily living (ADLs, such as walking around inside, bathing, dressing, and eating) and instrumental activities of daily living (IADLs, such as grocery shopping, preparing meals, light housework, and managing money). These survey data typically are interpreted to reflect the health status of the elderly population and are used to project public spending on Medicare and Medicaid programs, including demand for home-based and nursing home care. Analyses of self-reported survey data have found declines in disability over the past two decades, particularly in the IADLs (Cutler, 2001; Freedman, Martin, & Schoeni, 2002). While the decline in self-reported disability is likely an indicator of improved health among elders, it is unclear whether other factors may explain some of the disability decline. We hypothesized that elderly respondents who used various technologies and lived in environments that better facilitated ADL and IADL tasks would be less likely to report disability compared to respondents not using these forms of assistance, and that increased use of technologies and better environments may explain some of the observed disability decline.

We conducted a pilot study with two goals: first, to begin to understand the effect of environmental and technological factors on survey responses[Note] and second, to test the data collection methods used in the pilot test for a planned large nationwide survey of seniors. This research was supported by the National Bureau of Economic Research and the National Institutes on Aging.

This paper describes the complexities of data collection in a pilot survey of community-dwelling elders age 70 and older. The study involved a 20-minute in-person Computer-Assisted Personal Interview (CAPI) and a short physical assessment using the Short Physical Performance Battery (SPPB), a well-established performance test developed for the Established Populations for Epidemiologic Studies of the Elderly (Berkman et al., 1993; Ferrucci et al., 2000; Guralnik et al., 1994, 1995; Melzer, Tzuo-Yen, & Guralnik, 2003) and used in the Women’s Health Study (Ostir, Volpato, Fried, Chaves, & Guralnik, 2002), as well as in other surveys of community dwelling elders (Al Snih, Markides, Ostir, Ray, & Goodwin, 2003).

INSTRUMENTATION

The survey instrument was developed based on a review of the literature, qualitative interviews with members of the target population (*n* = 10), and cognitive interviews (*n* = 15). The instrument began with three disability questions from the National Long Term Care Study (NLTCS). In particular, we focused on whether a respondent had problems walking around inside and was able to prepare meals and shop for groceries "without help" (Manton, Corder, & Stallard, 1993). These three problem areas are focused on throughout the instrument. Follow-up questions determined if the problems were a result of a health condition, the expected duration of the problem, and whether respondents received any help for these problems in the last three months.

The next section asked about specific medical conditions, including arthritis, heart condition, and having broken a hip. A series of vignettes followed. Each vignette was gender-matched to the respondent and described imaginary persons with varying levels of mobility and functioning problems. Respondents were asked to decide whether the vignette described someone who could do the given task "without help." The next section went into more depth about walking around inside. A series of questions about grocery shopping followed. After the grocery shopping series, questions about preparing meals attempted to ascertain how the respondent prepared their meals, including use of different kitchen aids—such as dishwasher, microwave oven, etc. The instrument ended with demographic items and included a household listing and a question about total household income in 2005. Copies of the instrument are available on request.

Short Physical Performance Battery

We also obtained a performance-based measure of physical functioning with the SPPB. A summary performance score measuring lower-extremity function was constructed on the basis of three tests: standing balance, walking speed, and ability to rise from a chair. The standing balance test involves standing with feet in a side-by-side, semi-tandem, and full-tandem position for ten seconds each. The walking speed test measures how quickly respondents are able to complete a three-meter course while walking at their usual speed. The chair stand test requires respondents to sit in a straight-backed chair with their arms folded and to stand up without using their arms. If respondents successfully stand up, they are asked to repeat the chair stand five times as quickly as possible (Guralnick et al.,1994; Guralnik, n.d.).

Sampling

The frame for this household-level sample was the most recent city censuses available for the Massachusetts cities of Boston, Cambridge, and Somerville. A city census is conducted every year in these cities, and age of household member is on the census form. Previous experience suggests that approximately 85–90% of all people 70 or older are on the census lists, making these lists accurate and cost-effective for identifying this age group. The same cannot be said about these lists for other age groups. From the census lists, all unique addresses containing at least one person age 70 or older were eligible for selection into the sample. The sample lists were stratified by city, and a simple random sample of addresses was selected from within each city. The sample was selected within a city proportional to the number of 70+-year-olds living in the city. Very early in the field period, we declared addresses within a select group of six ZIP codes ineligible. Early experience interviewing within these ZIP codes, along with experience from other recent studies CSR conducted in the same locales, indicated that most people 70 or older within these ZIP codes did not speak English. The cost of attempting interviews within these ZIP codes was prohibitively high, while the expected yield of completed interviews was extremely low.

DATA COLLECTION PROCEDURES

Interviewer Training

The interviewers for this study attended a 1.5-day training session. All 12 professional field interviewers were women over age 40. The briefing began with a study overview and a question-by-question review of the instrument. The review also included an explanation of the use of "showcards" and how to handle nonstandard responses. Interviewers then were trained to conduct the SPPB using a video program and "warm practice," where the interviewers teamed up and practiced conducting the exercises on one another. The second day of training was devoted to additional practice on the laptops and learning data transmission procedures. Interviewers were tested on their proficiency at all required tasks.

Project Materials

Table 1 on the following page presents a listing of all of the field materials employed in this study.

PROCEDURES

The sample file was broken into smaller subsamples of about 150 households each. Interviewers were assigned specific geographic areas to cover within these subsamples. Because the sample was address based, interviewers were allowed to interview any eligible person in the household. Just two households had more than two eligible individuals willing to participate.

It was the responsibility of the interviewer to mail the introductory letter prior to going to a listed address. By allowing the interviewer to orchestrate this mailing rather than having it performed centrally at CSR, the interviewer had more control of sample management. This also ensured that the letter arrived close to the time the interviewer went to the household, rather than weeks ahead of time. The letters informed individuals who did not wish to participate in the study to call CSR to refuse an interview. Interviewers assigned the cases that refused were notified not to attempt interviews at those addresses. The prenotification letters also provided information for interested individuals to call CSR if they wished to make an appointment for an interview. These respondents provided their phone numbers, and we passed this information on to the appropriate interviewers.

No phone calls were made before going to the households unless the respondent had called CSR. Each contact with a potential respondent represents an opportunity for a refusal; the best chance to elicit cooperation for an interview occurs when the interviewer presents the study at the doorstep.

After letters were mailed, the interviewers went to the addresses listed on their assignment sheets. Potential respondents were offered a $20 cash incentive. All respondents who participated in an interview received the incentive; it was not necessary to undergo the physical assessment to receive the money.

Household Observation Form

After all the interviews in a household were finished, a household observation form was completed by the interviewer. This form contained questions about the respondent's cognitive ability—i.e., the perceived ability to understand the interview questions—and questions about certain physical characteristics of the interior and exterior of the dwelling.

QUALITY CONTROL/FIELD MANAGEMENT

Field interviewers audio taped their second and fifth interviews. The field manager then reviewed the tapes and worked with interviewers as needed to maintain quality control. Respondents were asked for their phone numbers to allow for a random sample from each interviewer to be called to verify that the interview was completed.

Each interviewer was required to have a weekly conversation with the field manager to discuss their cases. This call gave interviewers the opportunity to discuss the progress of the study, their personal progress, and any particular questions or problems that they had encountered. For example, they addressed first refusals, contact problems, address and/or language problems, and any issues that arose as a result of routine verification procedures. The manager and interviewer also identified the areas to be covered and whether additional sample was needed.

Table 1. Project Materials

ITEM	DESCRIPTION
Assignment Disposition Sheet	Included all cases assigned to the interviewer. Included each case's ID #, name, & address. Used to track each case's results & when talking to the Field Manager each week.
Cover Sheet	Each case had its own paper cover sheet. Used to record the each visit's outcome, to record a final result code, & as receipt for CSR to indicate that the respondent had received the incentive. Inside each was a simplified version of the SPPB scoring section.
Letters	Printed on Harvard letterhead & mailed in Harvard envelopes by the interviewer before visiting the household. Explained the study purpose, who the sponsors were, & how to contact CSR with questions/concerns. Each interviewer also had a supply of unaddressed/not personalized letters for respondents who had not received one.
Communication Tips for Elderly People Document	Contained tips on how to communicate with elderly people, including those who are hearing &/or visually impaired & those with cognitive difficulties.
Police Information Packet	Before the study began, letters were mailed to police stations throughout Boston, Cambridge, & Somerville explaining the study & advising that interviewers would be going to households in their area. Interviewers were given a list of all the police stations, with phone numbers, for the stations that had been contacted.
Fact Sheet	Contained basic study information (e.g., funder, what was involved in participating, how respondents were selected).
Show Cards (2)	Laminated, printed front & back, with instrument's closed-ended answer categories. Shown at specified questions to aid respondent recall of answer choices.
Informed Consent Form	Signed forms were required for respondents to participate in the SPPB. Explained physical tests' purpose, sponsor, researchers, what was involved, & risks. Printed in large font & signed by both participant & interviewer.
Interviewer Observation Sheet	Included items about respondent & descriptions of certain characteristics of the residence's interior & exterior.
Laptop	Instrument was programmed using CASES (Univ. of California Berkeley). When an interview was completed, the interviewer transmitted the data to CSR via the software program PcAnywhere.
Envelopes	Interviewers received 3 types: large business-reply envelopes to return cover sheets & scoring sheets; business-size envelopes to send in time & expense summaries; and small plain envelopes in which to place the respondent incentive (if the interviewer chose to use them).
Interviewer Identification	Laminated ID cards that included name, picture, the names of Harvard University & CSR, & study name.
Calling Cards	Cards with CSR contact information & space for writing a note to be left if no one answered at the sampled address.
Elder Abuse Cards	Cards with phone # of the MA Executive Office of Elder Affairs to be given to respondents who specifically asked for help. (None were distributed during the course of the study.)
Respondent Pay Form	Used to track distribution of cash incentives. Interviewer recorded interview date & ID # of paid respondent. Turned in to CSR on a weekly basis.
Call-In Report	Used to gather weekly information required by the field manager, including current status of interviewer's sample & amount of time spent on various tasks.
Time & Expense Summary Form	Used to record mileage, time, & expenses incurred (e.g., tolls). Mailed in weekly to CSR.
Audio Tape Recorder & Cassettes	Used to tape interviews for quality control review. With respondent's written permission, interviewers taped 2nd & 5th interviews, & throughout the field period, interviewers were instructed to record sporadic interviews for review.
Street Atlas	Interviewers were provided with books of maps for the areas they were assigned.
Materials for the SPBB	**Instruction sheet.** Printed on card stock. Included script for the tests & diagrams outlining the 3 tests. **Chain.** Used to measure walking course for gait speed test. Was slightly longer than 3 meters & had required length delineated by metal loops near each end. Was laid on the floor in a straight line to determine correct distance to mark off. **2"-wide painter's tape.** Placed on floor to delineate walking course's start & finish, allowing participant to clearly see the beginning & end of course. **Digital stopwatch.** Used to time all exercises. Some interviewers found it difficult to control; some had trouble clearing the screen. Future studies might invest in old-fashioned stopwatches with one start & stop button.

Table 2a. Results: Household Level

A. Total Number of Households in Sample	1,107

B. Ineligible Households	
TOTAL	148
Sample address not a dwelling unit	*9*
Sample address is group quarters	*69*
Sample address is vacant unit	*44*
Sample address in dropped ZIP code	*29*
C. Household Screened, No One Age 70+ Found	131
D. Household Screened, Someone Age 70+ Found	743
E. Household Not Screened, so Unknown if Someone Age 70+ in Household	85

1. Rate at which screened household had someone age 70+: D/(C + D) = 743/(743 + 131) = 85.0%

*2. Estimated number of households with someone age 70+ in unscreened households: E*0.85 = 85*.085 = 72*

Table 2b. Results: Person Level

F. Total Number of People Age 70+ Found	930
G. People Ineligible Due to Language	154
H. People Ineligible Due to Hearing Problem	3
I. People Eligible for Interview	773
J. Eligible People Who Completed Interview	441
K. Eligible People Who Did Not Complete Interview	332

1. Average number of people age 70+ in screened households: F/D=930/743=1.25

2. Eligibility rate of people age 70+ in screened households: I/F=773/930=83.1%

3. Rate at successfully interviewing screened eligible people age 70+: J/I=441/773=57.1%

*4. Overall survey response rate: J/((I + (72*1.25*0.831)) = 441/(773 + 75) = 0.520 or 52.0%*

DATA COLLECTION RESULTS

A total of 441 interviews were completed between January and April 2006 for an overall response rate of 52%. The most common reason for ineligibility was inability to speak English well enough to complete the interview. The languages most frequently encountered were Chinese, Spanish, and Russian. Reasons that eligible respondents were not interviewed included refusals (26%), cognitive problems identified either prior to the interview or by the respondent's inability to answer any three consecutive questions during the interview (2.3%), and an eligible respondent lived at the residence but was away for the duration of the study (1.8%). Also, there were 0.2% partial interviews that could not to be completed during the field period, and for 0.6%, there were other reasons for non-interviews. Table 2 presents the results of the data collection process at the household and person levels.

Approximately 84% of all respondents attempted the SPPB. Scores for the SPPB tests ran the full range of possible scores, from zero to twelve points. The most common reason for not attempting any of the tests was that the respondent could not hold the initial position unassisted.

DISCUSSION

The success of our data collection procedures may not be generalizable beyond the metropolitan Boston area—particularly to non-urban settings. We were fortunate that there were no major winter storms during the field period. Any blizzards might have driven down response rates, driven up data collection costs, and/or extended the field period. The quality of the field staff also played a major role in the success of this project. Our seasoned staff of professional interviewers had the experience necessary to elicit cooperation from the target population. The interviewers were all also "women of a certain age" who were presumably seen as nonthreatening by prospective respondents when they appeared at the door. This study was conducted in part as a pilot test for a nationwide survey of seniors. Despite early reservations about the feasibility of seniors' willingness to have interviewers come into their homes to conduct both a face-to-face interview and physical assessment tests, this study demonstrates that effective procedures for household interviews with urban elders can be implemented to make this an achievable goal.

REFERENCES

Al Snih, S., Markides, K. S., Ostir, G. V., Ray, L., & Goodwin, J. S. (2003). Predictors of recovery in activities of daily living among disabled older Mexican Americans. *Aging Clinical and Experimental Research, 15,* 315–320.

Berkman, L. F., Seeman, T. E., Albert, M., Blazer, D., Kahn, R., Mohs, R., et al. (1993). High, usual, and impaired functioning in community-dwelling older men and women: Findings from the MacArthur Foundation Research Network on Successful Aging. *Journal of Clinical Epidemiology, 46,* 1129–1140.

Cutler, D. M. (2001). Declining disability among the elderly. *Health Affairs, 20,* 11–27.

Ferrucci, L., Penninx, B. W., Leveille, S. G., Corti, M. C., Pahor, M., Wallace, R., et al. (2000). Characteristics of nondisabled older persons who perform poorly on objective tests of lower extremity function. *Journal of the American Geriatric Society, 48,* 1102–1110.

Freedman, V. A., Martin, L. G., & Schoeni, R. F. (2002). Recent trends in disability and functioning among older adults in the United States: A systematic review. *Journal of the American Medical Association, 288,* 3137–3146.

Guralnik, J. M. (n.d.). *Assessing physical performance in the older patient* [CD-ROM]. National Institute on Aging. Accessed May 22, 2007, at www.grc.nia.nih.gov/branches/ledb/sppb/

Guralnik, J. M., Simonsick, E. M., Ferrucci, L., Glynn, R. J., Berkman, L. F., Blazer, D. G., et al. (1994). A short physical performance battery assessing lower extremity function: Association with self-reported disability and prediction of mortality and nursing home admission. *Journal of Gerontology, 49,* M85–M94.

Guralnik, J. M., Ferrucci, L., Simonsick, E. M., Salive, M. E., & Wallace, R. B. (1995). Lower-extremity function in persons over the age of 70 years as a predictor of subsequent disability. *New England Journal of Medicine, 332,* 556–561.

Manton, K. G., Corder, L. S., & Stallard, E. (1993). Estimates of change in chronic disability and institutional incidence and prevalence rates in the U.S. elderly population from the 1982, 1984, and 1989 National Long Term Care Survey. *Journal of Gerontology, 48,* S153–S166.

Melzer, D., Tzuo-Yun, L., & Guralnik, J. M. (2003). The predictive validity for mortality of the index of mobility-related limitation: Results from the EPESE study. *Aging, 32,* 619–625.

Ostir, G., Volpato, S., Fried, L., Chaves, P., & Guralnik, J. (2002). Reliability and sensitivity to change assessed for a summary measure of lower body function: Results from the Women's Health and Aging Study. *Journal of Clinical Epidemiology, 55,* 916–921.

Stewart, K. A., Landrum, M. B., Gallagher, P., & Cutler, D. M. (2007). *Understanding self-reported disability in the elderly population.* Manuscript submitted for publication.

[Note] See Stewart, Landrum, Gallagher, and Cutler (2007) for the evaluation of whether increased availability and use of environmental and technological factors explained any of the disability decline over time. The results of those analyses are beyond the scope of this paper.

FEATURE PAPER: The Validity of Self-Reported Tobacco and Marijuana Use, by Race/Ethnicity, Gender, and Age

Arthur Hughes, *Substance Abuse and Mental Health Services Administration*
David Heller and Mary Ellen Marsden, *RTI International*

INTRODUCTION

Accurate information on the incidence and prevalence of alcohol, tobacco, and illicit drug use is critical to the development of meaningful and effective prevention and treatment programs. Because minorities continue to have some of the highest rates of various diseases, reducing or eliminating health disparities remains a priority in the federal government. African Americans and Hispanics have disproportionately higher rates of HIV/AIDS cases than Whites, and African Americans have lower survival rates for lung cancer than Whites (Office of Minority Health, 2005). With regard to drug use, Fendrich and Johnson (2005) showed that African Americans may provide less valid information on self-reported drug use than other racial/ethnic groups. Researchers and policymakers have long been concerned about the validity of self-reported drug use and have provided recommendations for improvement, including the use of biological specimens to validate self-reports (U.S. General Accounting Office, 1993). A National Institutes of Health strategic plan for reducing health disparities in drug abuse and addiction recommended improving the validity of self-reported drug use because minority populations may be differentially affected (National Institute on Drug Abuse [NIDA], 2004). The goal of this study is to examine the nature and extent of bias and discordance in self-reported estimates of tobacco and marijuana use by race/ethnicity, gender, and age compared with results from urinalysis tests in a nationally representative household survey.

BACKGROUND

Findings presented in this paper are based on a study of the validity of self-reported drug use data. This independent methodological study was modeled after the 2000 and 2001 National Household Survey on Drug Abuse (NHSDA), a multistage probability sample of the civilian noninstitutionalized population age 12 years old or older in the 50 states and the District of Columbia. Since 2002, the survey has been called the National Survey on Drug Use and Health (NSDUH; Office of Applied Studies, 2006). The Validity Study was developed by researchers at the University of Delaware, and the data collection was conducted by RTI International.[Note] Funding was provided by NIDA and the Substance Abuse and Mental Health Services Administration (SAMHSA). More complete findings from this study are available in Harrison, Martin, Enev, and Harrington (2007). The Validity Study used the NHSDA questionnaire and data collection methods, except that the Validity Study was conducted in the coterminous U.S. only, interviews were not conducted in Spanish, the sample was limited to persons age 12–25 in a sample separate from the main NHSDA, a maximum of one person per household was interviewed, and hair and urine specimens were collected. The NHSDA questionnaire was adapted to obtain information on time periods associated with the windows of drug detection in hair and urine. Because of problems encountered with the collection and analysis of hair specimens during the study (insufficient quantity for testing and few positive results), analyses comparing self-reports with the results of hair testing are not presented in Harrison et al. (2007) or in this paper.

The total number of respondents in the Validity Study was 4,465 over the two-year data collection period (2000 and 2001), with a 74.3% weighted interview response rate. Of those completing the interview, 89.4% provided hair, urine, or both; of these, 80.5% provided both, 4.7% provided only urine, and 4.3% provided only hair. Additional interview and urine speci-men response rates by race/ethnicity, gender, and age are presented in Table 1. Respondents received $25 each to provide a hair and a urine specimen, for a total of $50. Urine drug testing was conducted for cotinine (tobacco), marijuana, cocaine, opiates, and amphetamines.

Table 1. Response Rates & Sample Sizes for the Validity Study, by Demographic Characteristics

CHARACTERISTIC	Selected Persons[1]	COMPLETED INTERVIEW		PROVIDED URINE SAMPLE	
		# Respondents	Weighted Response Rate[2]	# Respondents	Weighted Response Rate
TOTAL	5,985	4,465	74.3%	3,810	85.1%
Race/Ethnicity					
White, non-Hispanic	3,848	2,866	74.8	2,447	85.1
Black, non-Hispanic	809	603	77.0	528	86.5
Other, non-Hispanic	352	323	73.5	260	85.4
Hispanic	954	673	70.3	575	84.0
Gender					
Male	2,898	2,161	74.5	1,873	86.6
Female	3,063	2,304	74.4	1,937	83.6
Age					
12–17	2,940	2,303	77.9	1,977	85.9
12–14	1,456	1,173	80.4	1,006	85.9
15–17	1,481	1,130	75.5	971	85.9
18–25	3,045	2,162	71.3	1,833	84.5
18–20	1,185	890	74.9	764	85.3
21–25	1,851	1,272	69.2	1,069	83.9

[1] Selected persons may have unknown screening information for race/ethnicity, gender, and the finer age categories (12–14, 15–17, 18–20, 21–25). Those cases have been excluded from the reported sample sizes of selected persons and the calculation of the weighted response rates for these demographic categories.

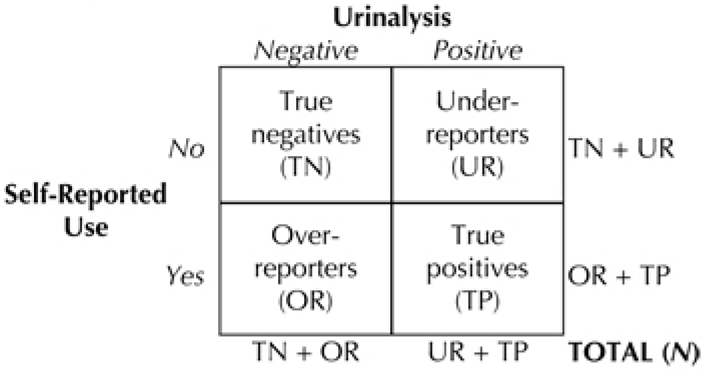
[2] Weighted response rates are computed using the number of respondents based on the screening by race/ethnicity, gender, and age, which may differ from the corresponding demographic categories for the final number of respondents reported in the second column of this table.

METHODS

For this report, a positive test for tobacco use was recorded if a respondent was found to have a concentration of 100 nanograms per milliliter (ng/mL) or more of cotinine, the principal metabolite of nicotine. Testing was done using an immunoassay test (i.e., enzyme-linked immunosorbent assay, ELISA). Tobacco testing results were compared with a respondent's self-reported tobacco use in the past three days. These data were captured in their answers to follow-up questions after their admission of past-month use of cigarettes, cigars, pipes, or smokeless tobacco. Respondents who reported no past-month tobacco use in previous questions were considered nonusers in the past three days. For marijuana, respondents whose urine specimens were screened to have a concentration of 30 ng/mL of marijuana (cannabinoids) or more and confirmed to have a concentration of 2 ng/mL or more of delta-9-tetrahydrocannabinol carboxylic acid (THCA) were recorded as testing positive. Either fluorescence polarization immunoassay (FPIA) or enzyme-multiplied immunoassay technique (EMIT) was used for screening, depending on when the sample was tested, and confirmation tests were done through gas chromatography/mass spectrometry (GC/MS) testing. Self-reported three-day use of marijuana was recorded in response to a similar follow-up question as that for tobacco; however, respondents also were asked about their past three-day marijuana use in a repeat question appearing later in the questionnaire. If a respondent reported past three-day use in either question, he or she was considered a past three-day marijuana user. Respondents who reported no three-day use in the follow-up question and did not have a valid response to the repeat question on past three-day use were excluded. Additionally, all respondents without a valid drug test were excluded from this analysis.

In addition to weighted prevalence rates of self-reported three-day use and positive test results, statistics comparing self-reporting and drug testing also are presented. These include estimates of discordance, underreporting and overreporting, bias, and correlation between discordance and bias. These measures are defined below and are based on variables in the 2x2 table shown in Figure 1. In Figure 1, TN, UR, OR, and TP are weighted totals, where the weights account for dwelling unit and person-level selection probabilities, nonresponse, and adjustment to census population estimates.

Figure 1. Relationship between Self-Reported Use & Urinalysis Test Results



		Urinalysis		
		Negative	*Positive*	
Self-Reported Use	*No*	True negatives (TN)	Under-reporters (UR)	TN + UR
	Yes	Over-reporters (OR)	True positives (TP)	OR + TP
		TN + OR	UR + TP	**TOTAL (*N*)**

P^{SR}= $(OR+TP)/N$ = Prevalence estimate based on self-reports.

P^{U}= $(UR+TP)/N$ = Prevalence estimate based on urinalysis results.

$$Bias(P^{SR}) = P^{SR} - P^{U}$$

$$= [(OR + TP)/N] - [(UR + TP)/N]$$

$$= (OR - UR)/N$$

$$Relative\ Bias(P^{SR}) = (P^{SR} - P^{U})/P^{U}$$

$$\begin{aligned} Variance(P^{SR} - P^{U}) &= (1/N^2)[Var(OR - UR)] \\ &= (1/N^2)\begin{bmatrix} Var(OR) + Var(UR) \\ -2Cov(OR,UR) \end{bmatrix} \end{aligned}$$

$$Discordance = (OR + UR)/N$$

$$Corr(bias, discordance) = \frac{[Var(OR) - Var(UR)]}{\sqrt{Var(OR - UR)Var(OR + UR)}}$$

Note that the bias and discordance measures are both a function of overreporting and underreporting. Tests of significance also were performed to determine if the bias was statistically different from zero (H_0: Bias = 0 vs. H_1: Bias ≠ 0). Using a Bonferroni adjustment for multiple comparisons, the alpha level was adjusted from $\alpha = .05$ to $\alpha = .05/11 = .0045$ to account for the 11 domains presented in Tables 2 and 3. These 11 domains consist of the total, 4 race/ethnicity categories (non-Hispanic White, Black, and "other," as well as Hispanic), 2 genders (male, female), and 4 age groups (12–14, 15–17, 18–20, 21–25). A correlation measure between bias and discordance was included to examine the association between these two measures of interest.

In addition to the comparative statistics presented in Tables 2 and 3, two logistic regression models predicting past three-day discordance of tobacco and marijuana were constructed. Models were fit with a permanent set of nine covariates, including gender, age, race/ethnicity, passive exposure in the past six months to tobacco or marijuana, and socioeconomic status (SES). SES was defined based on the 1990 Census long-form data. The four standard categories (metropolitan statistical area [MSA]/low SES, MSA/high SES, non-MSA/low SES, and non-MSA/high SES), based on block-group-level median rents and property values from both state and MSA data, were collapsed into two categories for this paper. MSA/low SES and non-MSA/low SES were combined to define low SES; high SES was defined in a similar fashion. The other four covariates in the initial set of variables were constructed from data captured in the debriefing section of the questionnaire. These include the following:

- *Appeal* (respondent did or did not receive appeal to answer questions completely and honestly),
- *Truthfulness* (respondent did or did not report answering questions related to substance use completely truthfully),
- *Difficulty in answering questions related to substance use* (a continuous measure constructed from four related debriefing questions), and
- *Privacy of the interview* (a continuous measure based on the interviewer's ranking of the level of privacy during the interview).

Table 2. Comparison Statistics & Prevalence Rates Based on Urinalysis Results & Self-Reported Past 3-Day Tobacco Use

DOMAIN	# Respondents	% Discordance[1] *(SE)*	% Overreporters[2] *(SE)*	% Underreporters[3] *(SE)*	% Self-Report Prevalence Rate[4] *(SE)*	% Positive Urine Prevalence Rate[5] *(SE)*	% Relative Bias[6]	Correlation between Bias & Discordance[7]
TOTAL	3,759	11.3 *(0.6)*	3.6 *(0.4)*	7.7 *(0.5)*	25.4 *(1.0)*	29.5[b] *(1.1)*	-13.7	-0.307
Race/Ethnicity								
White, non-Hispanic	2,417	10.9 *(0.7)*	4.0 *(0.6)*	6.8 *(0.6)*	29.3 *(1.3)*	32.1[a] *(1.4)*	-8.6	-0.025
Black, non-Hispanic	522	14.6 *(1.7)*	2.1 *(0.8)*	12.5 *(1.7)*	18.4 *(2.1)*	28.8[b] *(2.3)*	-36.2	-0.656
Other, non-Hispanic	257	7.8 *(2.1)*	2.1 *(1.1)*	5.8 *(1.7)*	21.6 *(3.1)*	25.3 *(3.3)*	-14.6	-0.439
Hispanic	563	11.7 *(1.6)*	4.0 *(0.8)*	7.7 *(1.5)*	16.5 *(1.9)*	20.3 *(2.0)*	-18.4	-0.535
Gender								
Male	1,844	11.2 *(0.9)*	3.4 *(0.5)*	7.7 *(0.7)*	27.3 *(1.3)*	31.7[b] *(1.3)*	-13.6	-0.332
Female	1,915	11.4 *(0.8)*	3.8 *(0.6)*	7.6 *(0.7)*	23.5 *(1.3)*	27.2[b] *(1.4)*	-13.8	-0.143
Age								
12–14	994	8.7 *(1.1)*	1.0 *(0.5)*	7.7 *(1.0)*	2.8 *(0.7)*	9.4[b] *(1.1)*	-70.4	-0.668
Age 15–17	958	12.7 *(1.3)*	2.8 *(0.6)*	9.9 *(1.2)*	17.8 *(1.6)*	24.9[b] *(1.9)*	-28.4	-0.600
Age 18–20	753	11.9 *(1.4)*	5.9 *(1.0)*	6.0 *(0.9)*	38.2 *(2.3)*	38.3 *(2.2)*	-0.2	0.092
Age 21–25	1,054	11.7 *(1.3)*	4.3 *(0.8)*	7.4 *(0.9)*	37.0 *(1.9)*	40.1 *(1.9)*	-7.6	-0.087

SE = standard error.

[a] Difference between bias (self-report prevalence rate - positive urine prevalence rate) and zero is statistically significant at the .05 level. (Bonferroni adjustment was applied for multiple testing.)

[b] Difference between bias (self-report prevalence rate - positive urine prevalence rate) and zero is statistically significant at the .01 level. (Bonferroni adjustment was applied for multiple testing.)

[1] *Discordance* (%) = percentage reporting no use and testing positive or reporting use and testing negative.

[2] *Overreporters* (%) = percentage reporting tobacco use in the past 3 days but tested negative for tobacco use.

[3] *Underreporters* (%) = percentage reporting no tobacco use in the past 3 days but tested positive for tobacco use.

[4] *Self-report prevalence rate* (%) = percentage reporting tobacco use in the past 3 days in follow-up questions from the Validity Study questionnaire.

[5] *Positive urine prevalence rate* (%) = percentage testing positive for tobacco in urinalysis. A cutoff concentration of 100 ng/mL was used to identify a specimen as positive for cotinine.

[6] *Relative bias* (%) = [(self-report rate - positive urine rate)/(positive urine rate)] x 100%.

[7] Pearson's correlation coefficient showing the correlation between the bias (self-report prevalence rate - positive urine prevalence rate) and discordance (disagreement between self-reported prevalence and urinalysis results).

Table 3. Comparison Statistics and Prevalence Rates Based on Urinalysis Results & Self-Reported Past 3-Day Marijuana Use

DOMAIN	# Respondents	% Discordance[1] *(SE)*	% Overreporters[2] *(SE)*	% Underreporters[3] *(SE)*	% Self-Report Prevalence Rate[4] *(SE)*	% Positive Urine Prevalence Rate[5] *(SE)*	% Relative Bias[6]	Correlation between Bias & Discordance[7]
TOTAL	3,749	7.0 *(0.4)*	1.7 *(0.2)*	5.2 *(0.4)*	7.9 *(0.6)*	11.4[a] *(0.6)*	-30.8	-0.451
Race/Ethnicity								
White, non-Hispanic	2,408	6.6 *(0.6)*	2.0 *(0.3)*	4.6 *(0.5)*	8.2 *(0.8)*	10.8[a] *(0.8)*	-23.8	-0.413
Black, non-Hispanic	522	8.8 *(1.3)*	0.5 *(0.3)*	8.3 *(1.3)*	8.1 *(1.6)*	15.9[a] *(1.9)*	-49.2	-0.879
Other, non-Hispanic	257	7.4 *(1.9)*	3.4 *(1.7)*	4.0 *(1.2)*	10.1 *(2.3)*	10.7 *(2.2)*	-5.3	0.357
Hispanic	562	6.6 *(1.1)*	0.9 *(0.4)*	5.7 *(1.2)*	5.1 *(1.0)*	9.9[a] *(1.7)*	-48.1	-0.801
Gender								
Male	1,842	7.9 *(0.7)*	1.6 *(0.3)*	6.3 *(0.6)*	9.8 *(0.8)*	14.6[a] *(0.9)*	-32.8	-0.545
Female	1,907	6.0 *(0.6)*	1.9 *(0.4)*	4.0 *(0.5)*	5.8 *(0.7)*	7.9[a] *(0.7)*	-26.9	-0.279
Age								
12–14	993	2.1 *(0.6)*	0.6 *(0.3)*	1.5 *(0.5)*	1.1 *(0.4)*	2.0 *(0.5)*	-43.2	-0.351
15–17	956	7.6 *(0.9)*	2.4 *(0.5)*	5.2 *(0.8)*	7.5 *(1.0)*	10.3 *(1.2)*	-26.9	-0.416
18–20	748	9.0 *(1.2)*	2.4 *(0.6)*	6.6 *(1.0)*	13.7 *(1.4)*	17.9[a] *(1.6)*	-23.5	-0.438
21–25	1,052	8.4 *(0.9)*	1.5 *(0.4)*	6.8 *(0.9)*	8.4 *(1.1)*	13.7[a] *(1.4)*	-38.9	-0.642

SE = standard error.

[a] Difference between bias (self-report prevalence rate - positive urine prevalence rate) and zero is statistically significant at the .01 level. (Bonferroni adjustment was applied for multiple testing.)

[1] *Discordance* (%) = Percentage reporting no use and testing positive, or reporting use and testing negative.

[2]

Overreporters (%) = Percentage reporting marijuana use in the past 3 days but tested negative.

[3] *Underreporters* (%) = Percentage reporting no marijuana use in the past 3 days but tested positive.

[4] *Self-report prevalence rate* (%) = Percentage reporting marijuana use in the past 3 days in follow-up or repeat questions from the Validity Study questionnaire.

[5] *Positive urine prevalence rate* (%) = Percentage testing positive for marijuana in urinalysis. A screening cutoff concentration of 30 ng/mL for cannabinoids and a confirmatory cutoff concentration of 2 ng/mL for carboxy-THC were used to identify a specimen as positive for marijuana.

[6] *Relative bias* (%) = [(self-report rate - positive urine rate)/(positive urine rate)] x 100%.

[7] Pearson's correlation coefficient showing the correlation between the bias (self-report prevalence rate - positive urine prevalence rate) and discordance (disagreement between self-reported prevalence and urinalysis results).

Additional measures of interest were considered in the modeling but were kept in the final models only if they were significant at $\alpha = .05$. These additional measures included the geographic characteristics of census region and population density, friends' use of cigarettes or marijuana, respondent's self-reported history of arrests for breaking the law, a composite measure of respondent's frequency of demonstrating risky/dangerous behavior, and a continuous measure of respondent's religiosity. "Religiosity" was composed of questions about the number of religious services attended in the past year, the importance of religious beliefs, how much religious beliefs influence decisions, and the importance of friends sharing religious beliefs. For this continuous measure, 1 indicates "not religious" and 15 "very religious." Respondents with unknown information for any of the covariate measures were excluded from the final models. Logistic regression model results are presented in Table 4.

RESULTS

Collection of Urine Samples

Overall, 85.1% of those age 12–25 provided a urine sample during the interview (Table 1). Urine acquisition rates decreased slightly with increasing age, with 85.9% of 12–14 and 15–17 year-olds, 85.3% of 18–20 year-olds, and 83.9% of 21–25 year-olds providing urine samples. A higher percentage of males provided urine samples than females (86.6% vs. 83.6%). An estimated 86.5% of Blacks, 85.1% of Whites, and 84.0% of Hispanics provided a urine sample.

Tobacco Use

Estimates of discordance associated with self-reported tobacco use in the past three days and urinalysis results are presented in Table 2. Among racial/ethnic groups, discordance was highest among Blacks (14.6%) compared to Whites (10.9%) and Hispanics (11.7%). Males and females exhibited a similar level of discordance (both about 11%). Within age groups, youths age 12–14 exhibited the lowest amount of discordance (8.7%) compared to between 11.7% and 12.7% for the older age groups. With few exceptions, discordance was driven by underreporting; overall, there were twice as many underreporters (URs) of tobacco use as overreporters (ORs) (7.7% vs. 3.6%). The greatest variation occurred among Blacks (12.5% vs. 2.1%) and youths age 12–14 (7.7% vs. 1.0%). The lowest variation occurred among 18–20 year-olds (6.0% vs. 5.9%).

Blacks and the youngest age group (age 12–14) had the highest absolute relative bias compared with others within their respective domains (36.2% and 70.4%, respectively), while the absolute relative bias was similar among males and females. Looking further at age differences, there was a negative relationship between absolute relative bias and self-reported prevalence. As self-reported prevalence increased with age from 2.8% (age 12–14) to 38.2% (age 18–20), the absolute relative bias decreased from 70.4% to 0.2%. For those age 21–25, three-day self-reported use was slightly lower at 37.0% compared with those age 18–20, while the absolute relative bias was higher at 7.6%.

The correlation between bias and discordance was moderately high for Blacks, Hispanics, and the two youngest age groups (between –0.535 and –0.656), near zero for Whites and the two oldest age groups, and low to moderate among other demographic groups (Table 2).

Unadjusted odds ratios showed that 15–17 year-olds were more likely to provide discordant responses than 12–14 year-olds, and Blacks were more likely to report discrepant responses than Whites. However, when controlling for SES and other variables, these relationships were no longer statistically significant (Table 4).

Marijuana Use

Estimates of discordance associated with self-reported marijuana use in the past three days and urinalysis results are presented in Table 3. Among racial/ethnic groups, discordance was highest among Blacks (8.8%)—slightly higher than among those of “other” races/ethnicities (7.4%) and Whites and Hispanics (6.6%). Discordance was higher among males than females, and among age groups, it was highest among the older age groups (ages 18–20 and 21–25). As with analyses of tobacco use, discordance was driven by underreporting; overall, there were three times as many URs of marijuana use as ORs (5.2% vs. 1.7%). The greatest variation between under- and overreporting occurred among Blacks (8.3% vs. 0.5%) and Hispanics (5.7% vs. 0.9%).

Blacks and Hispanics had higher relative bias than other racial/ethnic groups (49.2% and 48.1%, respectively, vs. 23.8% among Whites and 5.3% among other races/ethnicities). Relative bias was higher among males than females and highest among youths age 12–14 compared with other age groups. Similar to tobacco use, the prevalence of marijuana use increased with age among the three youngest age groups, while the relative bias decreased with age among the same groups.

The correlation between bias and discordance was high for Blacks and Hispanics (–0.879 and –0.801, respectively) and low to moderate among other demographic groups (Table 3).

Unadjusted odds ratios showed that all older age groups were more likely to provide discordant three-day marijuana use responses than those age 12–14 and that females were less likely than males and Blacks were more likely than Whites to report discrepant responses. Adjusted odds ratios showed that these relationships for Blacks and females were no longer statistically significant.

Table 4. Logistic Regression Models Predicting 3-Day Discordance of Tobacco & Marijuana Use

	3-DAY TOBACCO DISCORDANCE			**3-DAY MARIJUANA DISCORDANCE**		
	Unadjusted Odds	**Odds Ratio**	**95% CI**	***Unadjusted Odds***	**Odds Ratio**	**95% CI**
Intercept	*N/A*	0.03[b]	(0.01–0.06)	*N/A*	0.02[b]	(0.01–0.05)
Race/Ethnicity						
White	*1.00*	1.00	(1.00–1.00)	*1.00*	1.00	(1.00–1.00)
Black	*1.40*[a]	1.27	(0.90–1.79)	*1.37*[a]	1.14	(0.73–1.80)
Hispanic	*1.08*	1.38	(0.97–1.96)	*1.00*	0.88	(0.55–1.41)
Other	*0.69*	0.79	(0.45–1.41)	*1.14*	1.01	(0.52–1.95)
Gender						
Male	*1.00*	1.00	(1.00–1.00)	*1.00*	1.00	(1.00–1.00)
Female	*1.03*	1.10	(0.86–1.41)	*0.74*[a]	0.85	(0.64–1.14)
Age						
12–14	*1.00*	1.00	(1.00–1.00)	*1.00*	1.00	(1.00–1.00)
15–17	*1.53*[a]	1.29	(0.86–1.95)	*3.82*[b]	2.09[a]	(1.10–3.95)
18–20	*1.42*	1.11	(0.73–1.69)	*4.63*[b]	2.29[a]	(1.16–4.54)
21–25	*1.39*	1.16	(0.78–1.71)	*4.27*[b]	2.40[a]	(1.21–4.76)
SES						
High SES	*1.00*	1.00	(1.00–1.00)	*1.00*	1.00	(1.00–1.00)
Low SES	*1.42*[b]	1.23	(0.94–1.61)	*1.31*	1.21	(0.85–1.73)
Appeal						
With appeal	*1.00*	1.00	(1.00–1.00)	*1.00*	1.00	(1.00–1.00)
Without appeal	*1.27*	1.35[a]	(1.02–1.78)	*1.23*	1.20	(0.90–1.61)
Truthfulness						
Completely truthful	*1.00*	1.00	(1.00–1.00)	*1.00*	1.00	(1.00–1.00)
Not/somewhat/mostly truthful	2.63[b]	2.01[b]	(1.30–3.13)	*2.51*[b]	1.41	(0.85–2.31)
Past 6-Month Exposure[1]						
Never	*1.00*	1.00	(1.00–1.00)	*1.00*	1.00	(1.00–1.00)
Seldom	*0.58*	0.61	(0.34–1.11)	*4.47*[b]	3.19[b]	(1.94–5.25)
Frequently	*1.45*	1.30	(0.76–2.23)	*9.16*[b]	4.76[b]	(2.87–7.89)

Daily	*1.84*[a]	1.60	(0.93–2.76)	*8.09*[b]	3.09[b]	(1.49–6.40)
How Many Friends Use[2]						
None	*1.00*	1.00	(1.00–1.00)	*1.00*	1.00	(1.00–1.00)
A few	*2.16*[b]	1.78[b]	(1.25–2.53)	*2.22*[b]	0.91	(0.58–1.43)
Most	*2.28*[b]	1.35	(0.87–2.10)	*7.19*[b]	1.75[a]	(1.10–2.78)
All	*3.58*[b]	2.18[a]	(1.04–4.57)	*6.54*[b]	1.75	(0.76–4.03)
Region						
Northeast	*1.49*	1.26	(0.74–2.14)	*0.48*[b]	0.44[b]	(0.27–0.72)
Midwest	*2.04*[b]	1.83[a]	(1.10–3.06)	*0.68*	0.62[a]	(0.39–0.99)
South	*1.94*[b]	1.67[a]	(1.05–2.65)	*0.71*	0.74	(0.48–1.13)
West	*1.00*	1.00	(1.00–1.00)	*1.00*	1.00	(1.00–1.00)
Population Density						
MSA = 1 million	*1.00*	1.00	(1.00–1.00)	-	-	-
MSA < 1 million	*1.45*[a]	1.39[a]	(1.03–1.88)	-	-	-
Non-MSA	*1.08*	0.97	(0.68–1.39)	-	-	-
Privacy Summary Measure	*1.06*	1.04	(0.97–1.12)	*1.03*	1.03	(0.94–1.14)
Difficulties Summary Measure	*1.08*[b]	1.04	(0.99–1.10)	*1.09*[b]	1.08[b]	(1.02–1.14)
Religiosity Summary Measure	*0.94*[b]	0.96[a]	(0.92–1.00)	*0.88*[b]	0.94[a]	(0.89–0.99)
Ever Arrested for Breaking the Law						
Never arrested	-	-	-	*1.00*	1.00	(1.00–1.00)
Arrested	-	-	-	*3.07*[b]	1.58[a]	(1.06–2.37)
	Hosmer-Lemeshow χ^2 Test			**Hosmer-Lemeshow χ^2 Test**		
	χ^2 = 19.14	*df* = 8	*p* = 0.0141	χ^2 = 9.50	*df* = 8	*p* = 0.3016

CI = confidence interval. MSA = metropolitan statistical area. N/A = Not applicable. SES = socioeconomic status. — Not included in final model due to nonsignificance.

[a] Significant at the .05 level.

[b] Significant at the .01 level.

[1] *Past 6-month exposure* measure refers to exposure to cigarette smoke or other tobacco in the 3-day tobacco discordance model and exposure to marijuana smoke in the 3-day marijuana discordance model.

[2] *How many friends use* measure refers to smoking cigarettes in the 3-day tobacco discordance model and marijuana use in the 3-day marijuana discordance model.

DISCUSSION

Without exception, all self-reported estimates of tobacco and marijuana use exhibited a downward bias, meaning that underreporting occurred more frequently than overreporting. Blacks and youths age 12–14 had the largest bias compared with others in their respective demographic groups for both tobacco and marijuana use. Unadjusted odds ratios showed that older persons and Blacks were more likely than the youngest age group and Whites, respectively, to report discrepant responses compared with urine test outcomes; moreover, females were less likely to misreport than males. However, after controlling on SES, privacy, truthfulness, friends' use, and other theoretically relevant covariates, these relationships were no longer statistically significant, indicating that researchers finding significant racial/ethnic, gender, and age differences in measurement error should be aware of covariates that may mitigate these differences and help provide other explanations.

Because bias is defined in this analysis as the difference between ORs and URs, estimates based on self-reports will have small bias only if these two quantities are approximately equal. Ideally, OR and UR both should be equal to zero; however, estimates with little bias could correspond to nonzero and possibly significant discordance, whenever OR and UR are large and approximately equal. One example of this is 18–20 year-olds reporting tobacco use in the past three days. Nearly 12% provided discordant responses (OR = 5.9, UR = 6.0), yet the difference between the self-reported estimate and the percent positive urine specimens was only 0.1% (*p* = .94). The very low correlation between bias and discordance for tobacco use among 18–20 year-olds also shows that these two measures can behave quite differently. There appears to be a strong relationship between self-reported use and absolute relative bias by age. The youngest respondents (age 12–14) had the lowest use rates and highest absolute relative bias. This finding held for both tobacco and marijuana use and was driven by underreporting.

An important limitation of this study stems from the imprecision of the time of use indicated by the urine test. Many factors can affect the length of time after use that drugs will be detectable in urine. We chose a three-day reference period for the self-report measure because of the near certainty that any tobacco or marijuana use within the past three days would be detected. However, marijuana can sometimes be detected in urine for several weeks, particularly if the quantity used was large. Thus, some respondents who had last used just prior to three days ago and who self-reported (accurately) that they had not used in the past three days probably had a positive urine test and would have been counted as URs in our analysis. Thus, our estimates of underreporting (and, consequently, bias and discordance) are inflated to some unknown degree. Alternatively, the analysis could have focused on past-month self-report, virtually eliminating the overcount of URs but introducing other more frequent types of misclassification (e.g., light users who last used 4–30 days ago, denied past-month use, and had a negative urine would be coded as true negatives; if they did report use, they would be coded as ORs).

Future studies using biological specimens to validate self-reports should include appropriate kinds of specimens and questionnaire items so that the validity of self-reported drug use can be investigated for longer recency periods (e.g., past month). Although the examination of past three-day patterns of bias and discordance is useful, social desirability effects associated with reporting very recent substance use may produce a larger bias and discordance compared with those based on past-month use. It is important to be able to accurately match the window of detection with the recency period associated with the self-reported estimate. Information on the frequency and amount of substance consumed could help determine the appropriate classification in conjunction with the urine sample data or data from any other biological specimens. Finally, in this study, it was assumed that the urine test results were measured without error. However, this will seldom be the case, so it is important to consider other approaches to analyzing and presenting these kinds of data.

REFERENCES

Fendrich, M., & Johnson, T. P. (2005). Race/ethnicity differences in the validity of self-reported drug use: Results from a household survey. *Journal of Urban Health: Bulletin of the New York Academy of Medicine, 82*(Supplement 3), iii67–iii81.

Harrison, L. D., Martin, S. S., Enev, T., & Harrington, D. (2007). *Comparing drug testing and self-report of drug use among youths and young adults in the general population* (DHHS Publication No. SMA 07-4249, Methodology Series M-7). Rockville, MD: Substance Abuse and Mental Health Services Administration, Office of Applied Studies. Retrieved June 21, 2007, from http://oas.samhsa.gov/validity/drugTest.pdf

National Institute on Drug Abuse. (2004). *Strategic plan on reducing health disparities: NIH health disparities strategic plan, fiscal year 2004-2008* (revised July 2004). Retrieved May 25, 2007, from www.drugabuse.gov/PDF/HealthDispPlan.pdf

Office of Applied Studies. (2006). *Results from the 2005 National Survey on Drug Use and Health: National findings* (DHHS Publication No. SMA 06-4194, NSDUH Series H-30). Rockville, MD: Substance Abuse and Mental Health Services Administration. Retrieved June 21, 2007, from http://oas.samhsa.gov/NSDUH/2k5NSDUH/2k5results.htm

Office of Minority Health. (2005, November 17). *HHS Fact Sheet: Eliminating minority health disparities*. Retrieved May 25, 2007, from www.omhrc.gov/templates/content.aspx?ID=2138&lvl=2&lvlID=92

U.S. General Accounting Office. (1993, June 25). *Drug use measurement: Strengths, limitations, and recommendations for improvement* (GAO/PEMD-93-18). Washington, DC: Author. Retrieved June 21, 2007, from http://archive.gao.gov/t2pbat5/149657.pdf

[Note] RTI International is a trade name of Research Triangle Institute.

SESSION 2 DISCUSSION PAPER

Joseph Gfroerer, *Substance Abuse and Mental Health Services Administration*

THE NEED FOR VALID COMPARISONS

This session focuses on a topic of increasing importance to health survey researchers: the need to accurately measure health characteristics consistently across subpopulations and over time.

Eliminating health disparities has been identified by the U.S. Department of Health and Human Services (DHHS) as one of two overarching goals of the *Healthy People 2010* initiative. Specifically, the goal is to "eliminate health disparities among segments of the population, including differences that occur by gender, race or ethnicity, education or income, disability, geographic location, or sexual orientation" (DHHS, 2000, p. 11). In addition, the U.S. Surgeon General has cited the elimination of health disparities among minorities as a public health priority. As a result, there has been an increase in the volume of research on health disparities and a demand for continuously collected, comparable data on various health characteristics among population subgroups. Population groups of most concern are those perceived as vulnerable to health problems or with reduced access to health care because of discrimination, cultural differences, or poverty (Kilbourne, Switzer, Hyman, Crowley-Matoka, & Fine, 2006; Stewart & Napoles-Springer, 2003). Thus, much of the research on health disparities has involved looking at data by race, ethnicity, nativity, acculturation, income, and education, along with age, gender, and geographic area.

To meet these data needs, surveys need to be designed to provide health measures that are consistent across the different categories of many key variables. Although there has been an emphasis on vulnerable populations, such as racial and ethnic minorities, immigrants, rural populations, and those in poverty, accurate measurement by basic demographic variables, such as age, gender, region, and state is important too.

Age differences in measurement should be of primary concern, as health problems and survey design issues vary greatly across the age spectrum. There continues to be a need for health data on children, and an area of increasing concern is collecting health data on the growing population of older Americans.

Consistent measurement across geographic areas such as region, state, substate, and urbanicity is critical as well. Resource allocation is often based on data for regions, states, and substate areas. State and substate data also are used to assess the impact of new policies and programs. Furthermore, global health issues require comparable data across nations to assess needs and to evaluate the impact of international health initiatives.

Although this session has a focus on the cognitive aspects of questionnaires and the reliability and validity of measurement at the respondent level, the problem of assessing and attaining comparability across subgroups is much broader, involving sampling and coverage issues as well. Household surveys have been hampered by undercoverage of young adults, particularly young Black males, and by low response rates among the elderly. Telephone surveys don't cover nontelephone households and typically obtain response rates below 50%. Some ethnic groups of interest in disparities research may be undercovered due to incomplete listing in household surveys because of language barriers, cultural differences, or concerns about being identified to authorities. Even when listed, selected persons may decline to participate in interviews for the same reasons. Media attention on immigration reform could potentially cause reduced coverage or response rates among Hispanics, especially along the Mexican border. While state-by-state comparisons are best made with surveys that use consistent methodologies across states, wide variations in response rates could result in biased comparisons even when data collection methods are consistent. State-level response rates in the 2005 NSDUH ranged from 61% (New York) to 81% (Tennessee) (Wright, Sathe, & Spagnola, 2007). Also, interviewer effects are typically intertwined with PSU or state effects because individual interviewers usually cover a small geographic area, such as a metropolitan area or other confined area. Finally, there are situations where response bias may vary by state as a result of different cultural or legislative factors. For example, in states with more severe penalties for marijuana possession or stricter enforcement of laws, marijuana users may be more reluctant to report their use in a survey interview.

COMMENTS ON THE PAPERS

The five papers presented in this session exhibit diverse approaches to assessing reliability, validity, and comparability in the measurement of health.

Fleishman demonstrates a methodology for assessing measurement equivalence using multiple-indicator multiple-causes models (MIMIC). His analysis focuses on a composite variable based on ten items related to psychological distress, taken from the K6 (six items), the SF12 (two items) and the PHQ (two items) scales. This approach represents an excellent example of how useful information can be obtained about the validity of an instrument without additional expensive data collection. When there are existing data available, the method can be used to help develop new survey items or scales, minimizing differential item functioning at the design phase. Recognizing that the K6 items originally were selected based on their consistency across groups, this analysis provides reassurance that the items in the K6 are not biased in the context of the MEPS.

When using this kind of analysis to evaluate measurement equivalence, it is important to remember that multi-item scales constructed using Item Response Theory methods are greater than the sum of their parts. Individual items may be more or less relevant for certain populations, but measurement equivalence is the goal for the overall scale, not necessarily individual items. As Fleishman's analysis shows, the item asking whether everything is an effort does not have the same relevance for psychological distress among the elderly as it does for distress among younger respondents, but its selection as an item indicates it contributed adequately to the overall scale in the populations tested.

Table 1. Percent of Adults Reporting K6 Score of 13 or Greater, 2004

Characteristic	K6 Alone	K6 Preceded by Other MH Questions
AGE		
Total age 18+	12.2%	9.9%
18–25	20.2	13.7
26–49	14.0	10.4
50+	6.9	7.9
GENDER		
Male	9.4	7.7
Female	14.8	12.0
RACE/ETHNICITY		
White	12.2	9.8
Black	11.9	8.1
Hispanic	12.2	10.8

Recent findings from NSDUH point out the limitations of focusing only on the psychometric properties of mental health scales in assessing comparability. Significant context effects were identified with the K6 scale. In the 2004 NSDUH, the half sample that was administered the K6 alone reported higher scores than the half sample in which a series of mental health "stem" questions immediately preceded the K6. Table 1 shows that the prevalence of serious psychological distress was 23% higher with the "K6 only" sample, and the discrepancies varied by age (47% higher for age 18–25) and race/ ethnicity (47% higher for Blacks). Thus, it's critical to consider structural features of instruments that may influence score fluctuations (and possibly "equivalence") along with psychometric properties of scales.

Vernon et al. address an important topic: the quality of self-reports of colorectal cancer screening.

DHHS has identified cancer screening and management as one of six focus areas in which racial and ethnic minorities experience serious disparities in health access and outcomes. The strength of this study is in its comprehensive design, which includes collecting data from patient records for validation, re-interviews to measure reliability, and a random assignment to three separate modes (mail, phone, and face-to-face). The design will allow analyses of the relationship between reliability and validity, to determine if the respondents whose self-report was incorrect were more likely to change their response in the second interview. Further analysis of this data set also should address differences in reliability and validity by race and ethnicity. The high levels of overreporting FOBT and colonoscopy found in this study, apparently due to a social desirability effect, point to the need for more research to validate self-reports of colorectal cancer screening. In addition, the sample used in this study may not be generalizable due to the limited geographic area and population covered and the high refusal rate.

Kennet et al. present preliminary results from an important new study done within the National Survey on Drug Use and Health. The nationally representative sample of over 3,000 respondents re-interviewed with the entire NSDUH instrument will provide data on the reliability of many different kinds of questionnaire items and constructs, ranging from basic demographic questions to attitudinal scales and complex modules that determine substance use disorders and mental problems. The data presented by Kennet et al. indicate very good reliability for reporting of substance use behaviors, with no major differences across population groups, with the possible exception of youths, who report less reliably on several measures. Another area of concern is the results indicating poor reliability for Hispanics' reporting of substance abuse and mental problems. This includes the data on Serious Psychological Distress, which is based on the K6 scale assessed in the Fleishman paper, although NSDUH uses a past-year reference period, while the MEPS data analyzed by Fleishman is based on a 30-day reference period.

Gallagher et al. address another aspect of comparability—making comparisons over time when key characteristics of the population related to the measure of interest are changing. In this case, the problem is that with the increasing availability of assistive technologies and other aids that may reduce the impact of disabilities, it is not clear that the downward trend in self-reported disability reflects improved health or is an artifact. By collecting more in-depth information using vignettes and physical tests, the researchers plan to answer this question. While this may seem like an unusual problem unique to the study of disability, it actually represents an issue faced quite often in health surveys. How can the presence of a health condition be consistently measured in a population in which some persons are untreated and others are receiving treatment that reduces or eliminates the symptoms of the condition? This is an issue not only if treatment rates change over time, complicating trend assessment, but also if treatment rates vary across population subgroups, affecting comparisons and the study of disparities.

Hughes et al. present data from a validity study done in conjunction with the NSDUH (Harrison, Martin, Enev, & Harrington, 2007). This study demonstrates that it is possible to get good cooperation rates for collecting urine and hair in a general population survey but also shows the difficulties in identifying an accurate, comparable criterion measure for validating self-reports. The hair samples collected were not useful in validating self-reports, and interpretation of the urine results is difficult due to the uncertainties about the time period represented by the urine tests. Nevertheless, the data are consistent with prior studies that have found higher levels of underreporting of substance use among Blacks (Johnson & Bowman, 2003). Both NSDUH and Monitoring the Future (MTF) showed lower rates of marijuana use among Black youths and young adults compared with Whites in 2000 and 2001, and the Youth Risk Behavior Surveillance System (YRBSS) showed rates for White and Black high school students that were about equal. But the urine tests from Hughes et al. show that Blacks age 12–25 had a 50% higher rate of use than Whites, as seen in Table 2.

Table 2. Percentage Using Marijuana in Past Month Based on Self-Report Surveys and Validity Study, by Race/Ethnicity

STUDY	Non-Hispanic White	Non-Hispanic Black	Hispanic
NSDUH, 12–17, 2001	8.5%	5.8%	7.5%
NSDUH, 18–25, 2001	17.9	15.0	10.2
MTF, 8th Grade, 2000-01	8.4	8.1	12.6
MTF, 10th Grade, 2000-01	20.2	16.7	20.5
MTF, 12th Grade, 2000-01	22.9	17.0	22.1
YRBSS, 9th–12th Grade, 2001	24.4	21.8	24.6
Validity Study Self-Report (3-day), 12–25, 2000–01	8.2	8.1	5.1
Validity Study Urine Test, 12–25, 2000–01	10.8	15.9	9.9

However, multivariate results (predicting marijuana discordance in a logistic regression model) show that Blacks were no more likely than Whites to provide discordant responses after controlling on socioeconomic status, passive exposure to marijuana smoke, being truthful in answering drug use questions, and other relevant covariates. The correlation between bias in self-reported marijuana prevalence and marijuana discordance was very high for Blacks (-.879), suggesting that a model depicting the bias in self-report prevalence would not show a statistically significant difference between Blacks and Whites based on these same covariates.

Comparisons of NSDUH and MTF estimates of marijuana use by grade show an increasing ratio of NSDUH to MTF with increasing grade, suggesting that underreporting in the household, relative to in-school data collection, decreases with age among youths (Gfroerer, Wright, & Kopstein, 1997). Brener et al. (2006) found evidence of this differential bias as well in a study associated with the YRBSS. The validity study results are consistent with these findings, as seen in Table 3.

Table 3. Estimates of Percentages of Students Using Marijuana in the Past Month, Spring 2001

Grade/Age	Ratio of MTF to NSDUH Prevalence	Ratio of Urine Test to NSDUH 3-Day Self-Report
8th/12–14	2.49%	1.82%
10th/15–17	1.55	1.37
12th/18–20	1.48	1.30

FUTURE CHALLENGES & RECOMMENDATIONS

Trends in the demographics and other characteristics of the United States population point to the need for new approaches to designing and evaluating health surveys. Most notably, the nation is becoming more culturally diverse, and the population is becoming older. The Census Bureau

(2004) projects that between 2000 and 2020, the percent of the population that is Hispanic will grow from 12.6 to 17.8, and the percent Asian will increase from 3.8 to 5.4. The percent over age 65 will increase from 12.4 to 16.3. The aging population demands new data collection tools that can measure health indicators accurately and consistently for older adults who often are institutionalized, mentally and physically impaired, difficult to contact because of gatekeepers and controlled access, and unwilling to participate when they are contacted for surveys (Murphy, Eyerman, & Kennet, 2004).

The greater need for surveys to provide comparable estimates is not independent of other challenges facing survey designers. Declining budgets for data collection and methodological research will make it difficult to adequately do the methodological work necessary to ensure comparability and to assess it after data are collected. The general trend in surveys of declining response rates can only have a negative impact on comparability. Given the importance of comparability, careful consideration needs to be given to any proposed use of the increasingly advocated multimode approaches to surveys. Design optimizations should include consideration of comparability across subgroups and over time. In some cases it may be desirable to allow more bias in overall estimates in order to reduce bias for comparisons. This is consistent with the basic principle that should be followed in designing any survey: the design should reflect and facilitate the particular analyses that will ultimately be applied to the data that is collected.

One of the most important challenges survey methodologists face on this issue is communication. Most of the general public recognizes that estimates generated from surveys are not comparable when questions are worded differently or when definitions are not consistent. While survey researchers understand that coverage differences, nonresponse bias variations, mode effects, context effects, incentive effects, and differential item functioning can affect comparability, these subtle factors are not recognized as problematic by many data users. The impact of these factors is not well understood by those outside the survey research field, so they often are overlooked or dismissed by policymakers, the media, and even some researchers. Examples are easy to find in substance abuse epidemiology research literature. Survey researchers need to find better ways to inform data users of these important limitations of survey data. This is critical at both the design phase and in the reporting of results.

REFERENCES

Brener, N. D., Eaton, D. K., Kann, L., Grun Baum, J. A., Gross, L. A., Kyle, T. M., et al. (2006). The association of survey setting and mode with self-reported health risk behaviors among high school students. *Public Opinion Quarterly, 70,* 354–374.

Gfroerer, J., Wright, D., & Kopstein, A. (1997). Prevalence of youth substance use: The impact of methodological differences between two national surveys. *Drug and Alcohol Dependence, 47,* 19–30.

Harrison, L. D., Martin, S. S., Enev, T., & Harrington, D. (2007). *Comparing drug testing and self-report of drug use among youths and young adults in the general population* (DHHS Publication No. SMA 07-4249, Methodology Series M-7). Rockville, MD: Substance Abuse and Mental Health Services Administration, Office of Applied Studies. Retrieved July 11, 2007, from www.oas.samhsa.gov/validity/drugTest.cfm

Johnson, T. P., & Bowman, P. J. (2003). Cross-cultural sources of measurement error in substance use surveys. *Substance Use & Misuse, 38,* 1447–1490.

Kilbourne, A. M., Switzer, G., Hyman, K., Crowley-Matoka, M., & Fine, M. J. (2006). Advancing health disparities research within the health care system: A conceptual framework. *American Journal of Public Health, 96,* 2113–2121.

Murphy, J., Eyerman, J., & Kennet, J. (2004). Nonresponse among persons age 50 and older in the National Survey on Drug Use and Health. In S. B. Cohen & J. M. Lepkowski (Eds.), *Eighth Conference on Health Survey Research Methods* (pp. 73–78). Hyattsville, MD: National Center for Health Statistics.

Stewart, A. L., & Napoles-Springer, A. M. (2003). Advancing health disparities research: Can we afford to ignore measurement issues? *Medical Care, 41,* 1207–1220.

United States Census Bureau. (2004). Projected population of the by age and sex: 2000 to 2005. From *U.S. interim projections by age, sex, race, and Hispanic origin.* Retrieved March 18, 2004, from www.census.gov/ipc/www/usinterimproj/

U.S. Department of Health and Human Services. (2000). *Healthy people 2010* (Vol. 1, 2nd ed.). Washington, DC: U.S. Government Printing Office.

Wright, D., Sathe, N., & Spagnola, K. (2007). *State estimates of substance use from the 2004–2005 National Surveys on Drug Use and Health* (DDHS Publication No. SMA 07-4235, NSDUH Series H-31). Rockville, MD: Substance Abuse and Mental Health Services Administration, Office of Applied Studies.

SESSION 2 SUMMARY

Vicki Burt, *National Center for Health Statistics*, and Todd Rockwood, *University of Minnesota*

This session focused on the concern that measurement error could either obscure health disparities in population subgroups or produce estimates of disparity where none exist.

Differential item functioning (DIF) of survey items may produce observed variation in subgroup analysis not because there is a difference in the underlying condition of interest, but because the respondents in the subgroups interpreted the question differently. That is, it may be measurement error. John Fleishman (AHRQ) presented an example of using the multiple-indicator multiple-causes (MIMIC) models to assess DIF or measurement nonequivalence. In this example using ten items related to mental health status, no DIF was detected. Most of these measures had been subject to DIF analysis prior to inclusion in the survey, and those with DIF were excluded from the questionnaire.

This approach can be utilized in the evaluation of measures when multicultural research is done. This approach will permit analysts to potentially avoid attributing measurement differences to cultural differences.

Vernon presented a comprehensive study of the reliability and validity of four colorectal cancer screening test self-reports (home fecal occult blood test, sigmoidoscopy, colonoscopy, and barium enema). The validity was determined by comparison to medical records. In this instance, a homogeneous population was selected. The validity estimates were evaluated for three modes of administration (mail, telephone, and face-to-face). Additionally, test-retest reliability of the questionnaire was assessed using three time periods (two weeks, three months, and six months). This study is an exemplary example of how to evaluate questionnaire items when it is anticipated the questions will be used broadly in terms of varying modes and length of recall.

Kennet presented results of a large reliability study conducted for the National Survey of Drug Use and Health (NSDUH). In 2006, 3,100 NSDUH respondents were reinterviewed 5–15 days after their first interview. Items evaluated weren't limited to drug use questions but to more general health questions (high blood pressure), some scales (K6 psychological distress scale), and health insurance and utilization. Reliability was assessed for non-Hispanic Blacks, non-Hispanic Whites, and Hispanics. However, due to the low proportion of NSDUH interviews completed in Spanish, reliability was not evaluated in Spanish.

Gallagher described a pilot test designed to monitor disability in older persons to assess if differential response is influencing observed trends. In particular, there is concern that the availability and use of new technologies and environmental and behavioral modifications decreases respondents' propensity to report disability. This study evaluated the correlation between raw survey responses, responses adjusted for observable characteristics, vignette-adjusted survey responses, and actual physical functioning to understand whether differential reporting may be occurring.

Finally, Hughes presented a study of the validity of self-reported drug use across race and ethnic subgroups. Four hundred NSDUH respondents received remuneration for a hair and/or urine specimen, and 80% provided a sample. Respondents were asked about three- and seven-day use of tobacco and marijuana (as well as other substances, findings for which were not discussed during this presentation). For both tobacco and marijuana, more underreporting than overreporting occurred. While it initially appeared that Blacks were more likely than Whites to report discrepant responses compared with urine test outcomes for both tobacco and marijuana, the relationships did not remain statistically significant after theoretically relevant covariates were added to the model.

The discussant reviewed other sources of bias that might affect subgroup estimate comparability.

These five interesting papers highlighted approaches to evaluating measurement error that may be due to differences in understanding, differences in recall and potentially differences in truthfulness and stimulated a wider ranging discussion.

Floor discussion of validity focused on two issues: (1) evaluation of the validity of a survey item across populations and (2) comparison of self-reported data to biological or physical markers.

Relative to the first issue, audience members raised a number of different questions that fall into the general categories of interviewers and translation/cultural issues relative to instruments and administration. The discussion regarding interviewers focused on the fit between the knowledge and skills of interviewers and the substantive focus of the research (e.g., nurses used as interviewers in the assessment of functional status in the elderly). A second interviewer-related topic was the fit between the interviewers and the population (e.g., matching on gender, ethnicity), and discussion focused on the trade-offs associated with purposive selection of interviewers. For example, because of professional training, nurses might be more likely to encourage and motivate respondents to perform, which could affect measurement; at the same time, their professional credentials may or may not reduce nonresponse. The discussion around ethnicity addressed interviewer-respondent matching and took into consideration cultural and translation issues associated with survey instruments. Survey methods are primarily a form of "White middle-class" communication, and we are not just overcoming translation issues associated with surveys but also overcoming cultural issues associated with the methodology itself. Participants clearly acknowledged the need for further effort on translation and administration around diverse cultures; however, the costs of the work are large and accepted standards around cultural competency and survey methods have not yet been fully articulated.

Regarding the second issue—comparison of self-reported data to a biological or physical marker—two concerns emerged: (1) how do we procure samples, and (2) how are they used in validity analysis? Discussion on sample procurement focused on the rate at which respondents are willing to offer one, two, or more biological samples or refuse collection of such samples; is refusal differentially split across individuals who do indicate drug use as opposed to those who do not? The concern was that there might be a relationship between the biological markers being sought and willingness to participate in a survey. Specifically, those who are likely to test positive make up the majority of those who refuse. The issue remaining to be addressed is whether there is a systematic relationship between engaging in/abstaining from the self-reported behavior and the samples being collected, and if so, what can be done to deal with the potential refusal differential?

Other themes that emerged during the discussion ranged from the principles associated with using a "gold standard" methodology, to how we should deal with the constraints that data collection places on our ability to make comparisons. Discussion of the latter centered on different timeframes often associated with self-report vs. biological markers. This included the timing of measurement, as well the ability to map self-reports onto available biological data. For example, in the NSDUH, respondents are typically asked about substance use during the past 30 days, yet available biological markers, such as urine tests, have a much shorter detection window. This issue of differences in detection windows was a repeated theme, as was and the importance of recognizing that an unknown amount of the false positives and false negatives is likely due to these differences.

Additional discussion focused on the inconsistency between self-report and biological markers in the case of overreporting—that is, drug use is self-reported but no biological marker is found. It was noted that "gold standards" are fallible, and this could be the source of some of the error. It also is possible that the desire to report no drug use may not be the same across all parts of the population. There is some evidence to suggest, for example, that some adolescents overreport substance use.

There was also discussion about the use of validity correction factors to introduce statistical adjustments for overreporting or underreporting. In this approach, a detailed set of information (self-report, biological) is obtained from a portion of the sample and used as an adjustment for the remainder of the sample. It was indicated that there are strengths to such an approach, but concerns exist about the influence that correction factors can have on the overall covariate measures.

The final validity-related issue discussed was how validity is conceived; it was argued that the "gold standard" model is not necessarily the ideal model. Instead, a model drawing on triangulation or multiple operationalism may be a more preferred model to evaluate and establish validity.

INTRODUCTION TO AND DISCUSSION OF SESSION 3: Challenges of Collecting Survey-Based Biomarker and Genetic Data

Timothy J. Beebe, *Mayo Clinic College of Medicine*

INTRODUCTION

It is becoming increasingly apparent that a fuller understanding of health and health outcomes will require the simultaneous collection and analysis of data related to genes, the environment, and behaviors. The household survey appears to be an ideal medium for the collection (or linking) of these various types of information. While the household survey has long been used to collect vast amounts of data related to demographic, social, psychological, and behavioral influences on health and health outcomes, the collection of the types of biological measures listed in Table 1 ushers in a host of new benefits. As Weinstein and Willis (2000) indicate, the benefits of linking biological measures with survey data include (1) obtaining population-representative data from nonclinical samples, (2) calibrating self-reports with other measures of health and disease, (3) explicating pathways and elaborating causal linkages between social environment and health, and (4) linking genetic markers with survey materials. The papers in this session reflect the range of topics that can be informed by this design, including aging (Smith et al.), psychiatric illness (Boyle et al.), breast cancer (Parsons et al.), general illness and injury (Johnson et al.), and adolescent health (Ladner). The coupling of survey and biomeasure data is also responsible for enhancing our understanding of the determinants of and treatments for a range of diseases, including various cancers, cardiovascular disease, gastrointestinal disease, arthritis, and substance abuse disorders.

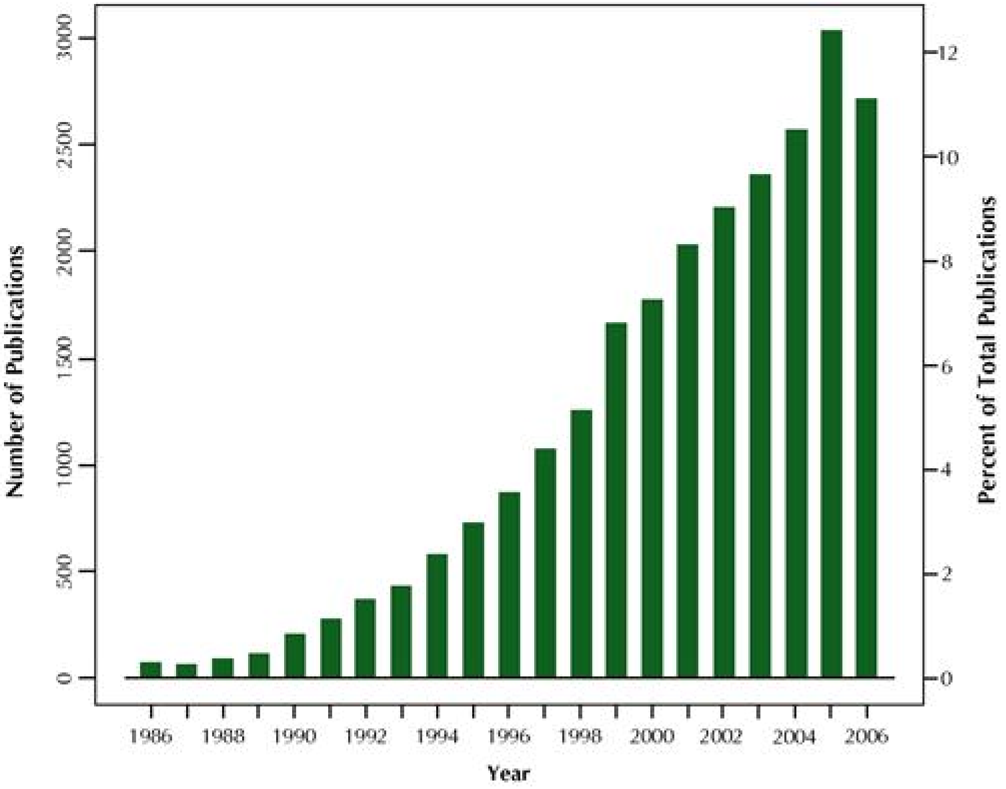
Table 1. Biological Measures Related to Demographic, Social, Psychological, & Behavioral Influences & Health Outcomes

	SOURCE
Cardiovascular System	
Systolic blood pressure	Exam
Diastolic blood pressure	Exam
Metabolic System	
Body mass index/waist-hip ratio	Self-report/exam
Total cholesterol	Blood
HDL/LDL cholesterol	Blood
Homocysteine	Blood
Glycosylated hemoglobin	Blood
Inflammation & Coagulation Factors	
IL-6, CRP, low cholesterol	Blood
Albumin	Blood
Fibrinogen	Blood
Antioxidant Profiles	Blood
Hypothalamic Pituitary Adrenal Axis	
Cortisol	Urine
DHEAS	Blood
Sympathetic Nervous System	
Norepinephrine	Urine
Epinephrine	Urine
Renal Function	
Creatinine clearance	Blood/urine
Lung Function	
Peak flow rate	Exam

Source: Crimmins & Seeman (2000).

There is evidence that surveys are increasingly including biomarker and genetic data (hereafter referred to as "biomeasures"). Using the key words "(survey OR questionnaire) AND (biospecimen OR biomarker OR gene OR genotype)," we conducted a PubMed search for articles that indicate the use of both biomeasure and survey data and present the results in Figure 1. It is apparent from this figure that the publications with survey-based biomeasure data have increased in the past 20 years, both in terms of raw numbers of publications and percentage of total publications. For example, within just the last decade, a threefold increase in the number of publications with a reference to survey-based biomeasure collection was observed, with approximately 1,000 publications of this nature in 1996 and 3,000 in 2006, or about 12% of the total number of publications for the latter year. Clearly, the collection or linking of biomeasure and survey data is on the rise.

Figure 1. Publications with Survey-Based Biomeasure and/or Genetic Data, by Year (1986-2006)



The collection of biomeasures can be undertaken a number of ways, including collection with an interviewer present and measurements actually made by the interviewer, collection without an interviewer present (e.g., as part of an RDD survey), and data collection not based in a household setting (e.g., in-clinic or mobile lab). The diversity of data collection approaches can be seen in the various session papers and are summarized in Table 2. A quick summary of the session papers will help put the balance of this paper into perspective. In their paper, Smith, Jaszczak, and Lundeen describe their experience with the National Social Life, Health, and Aging Project (NSHAP), a nationally representative survey of 3,005 older adults that utilizes in-person interviews and collects a wide range of biomeasures, including saliva, blood, and vaginal swabs. Boyle and colleagues describe their experiences with the 2004 Florida Hurricanes Gene and Environment Study, an RDD survey of 1,543 adult residents of Florida counties hit by hurricanes that also attempted to collect saliva samples. Parsons and colleagues describe the challenges of undertaking their Breast Cancer Care in Chicago project, which is composed of 925 in-person interviews with a diverse sample of Chicago residents with a breast cancer diagnosis and the collection of blood samples. Johnson and co-authors offer insights to a rich set of experiences collecting data for the National Health and Nutrition Examination Survey (NHANES), a nationally representative survey of adults that utilizes in-person interviews conducted in mobile examination centers where blood, urine, and saliva specimens also are obtained. Finally, Ladner and colleagues describe the operational issues surrounding the incorporation of biomarkers into the fourth wave of the National Longitudinal Study of Adolescent Health (Add Health), a nationally representative panel of 17,000 adolescents that relies on household in-person interviews and the collection of blood, saliva, and urine samples. Finally, the Koenig paper points out that these types of data collection are being undertaken in an ever-changing regulatory environment where the status of and access to genetic data is unclear. In general, laws regarding genetic information are not consistent. Most are related to genetic discrimination, usually relating to employment or insurance, although genetic discrimination has not been a problem yet. The impact of the current and emerging discussions at the legislative level on survey-based biomeasure collection is unclear.

Table 2. Overview of Samples, Data Collection Methods, and Biomeasures Used in the Session Papers

Author(s)	Sample	Method	Biomeasure(s)
Smith et al.	Nationally representative sample of older adults (*n*=3,005)	Household in-person interviews	13 measures including • Saliva • Blood • Vaginal swabs
Boyle et al.	Adult residents in Florida counties hit by hurricanes (*n*=1,543)	Household telephone interviews	Saliva
Parsons et al.	Diverse sample of Chicago residents with breast cancer diagnosis (*n*=925)	Household in-person interviews	Blood
Johnson et al.	Nationally representative sample of adults	In-person	Blood Urine Saliva Others (?)
Ladner	Nationally representative panel of adolescents (*n*=17,000)	In-person	Blood Saliva Urine

The increasing number of studies reliant on the coupling of biomeasure and survey data, combined with the aforementioned benefits of collecting both survey and biomeasure data and the unclear regulatory environment of genetic data collection, underscores the importance of the topic of this session. However, the extent to which the increasing collection of survey and biomeasure data have been informed by the survey methodological literature is unclear, as the methods deployed in the collection of biomeasures in surveys vary widely. It is in this context that the session was organized and undertaken. The session goals were threefold: (1) address the practicalities of biomeasure collection in surveys, (2) provide an overview of the current "state of the art" in biomeasure collection and analysis, and (3) understand the ethical and legal considerations associated with collecting biomeasure data in surveys. The overarching goal of the session was to advance our understanding of "best practices" in this emerging application of survey methods. In this paper, I will review the common challenges faced by survey researchers that emerged from the papers in this session and list some questions that remain unanswered. The latter may be construed as an emerging research agenda for survey methodologists interested in this topic.

COMMON CHALLENGES

A number of common challenges emerged from the papers, including the selection of the data collection platform, selection of interviewers, selection of the biomeasures and equipment, obtaining consent, and quality control. Each of these is discussed below.

Selection of the Data Collection Platform

For purposes of this section, the term "data collection platform" includes method of data collection (e.g., mail, telephone, or in-person) and location (e.g., household- vs. clinic-based). Decisions surrounding the former often center on the trade-offs of cost vs. quality. As Smith et al. indicate in their paper, a mailed survey may be the most inexpensive method of collection but one limited in the range and complexity of biomeasures that can be collected. The in-person interview allows for the widest range of biomeasure collection, but it is also the most expensive. An in-person interview conducted in the clinic setting may offer an even better range of biomeasure collection due to the availability of relevant biospecimen collection equipment, but some respondents may be disinclined to come into the clinic or may be otherwise hampered in their ability to do so due to lack of insurance and transportation.

Respondent capacity and motivation also have some bearing on what data collection platform is used. As mentioned above, some respondents may be disinclined to come into a clinical setting for the interview and/or biomeasure collection. Similarly, respondents may be unwilling or unable to follow the necessary instructions for the collection of the relevant biomeasure collection, even if it is something as relatively simple as a buccal swab. Again, there are trade-offs in the selection of method that figure in cost, quality, respondent capacity, and motivation.

Selection of Interviewers

If one is to pursue the use of an in-person interview, there appears to be a lack of consensus on what type of interviewer is best suited to undertake both the survey and biomeasure collection. In NHANES, Johnson et al. found that phlebotomists as interviewers increased the quality of the data and conclude that training phlebotomists to be interviewers is easier than the converse (training interviewers to draw blood). However, Smith and colleagues found it easier to train interviewers to collect the biospecimens than to train health care workers to be interviewers for the NSHAP. Clearly, training is a crucial component of biomeasure collection, whichever tack is taken by researchers. Interviewers also need to have buy-in and be willing to work with the specimens, such as keeping saliva vials in their freezers. Medical malpractice insurance may be necessary for interviewers who are not medically trained. Both Smith et al. and Ladner offer nice primers on how best to train interviewers to collect a wide range of biomeasures.

Selection of Biomeasures & Equipment

In her paper on the Add Health project, Ladner does a nice job detailing the calculus underlying the selection of various biomeasures. When doing face-to-face collection, all materials must be lightweight, easy to carry, and possible for lay interviewers to collect. As is the case with the selection of the data collection platform, decision making in this realm is guided by trade-offs between cost and data quality. Historically, blood draws have been the gold standard, as they are seen as providing the greatest yield of whatever is sought (e.g., DNA). However, the collection of blood is often the most expensive since it requires in-person interviews for the most part and the potential use of phlebotomists, as with HANES. But even within the realm of saliva collection, there is variability in cost and quality. King and colleagues (2002) found that buccal swabs and mouthwash offer DNA samples of comparable quality but that swabs are about half the price per sample of mouthwash rinses ($8.50 vs. $18.00, respectively) and that respondents found the swab instructions easier to follow. A common approach in genetic epidemiology is to ask for blood first and collect saliva if blood collection is refused (Lum & Marchand, 1998). Packaging and shipment of specimens is very important, and costly as well. Different specimens need to be shipped in different ways; a system should be in place to track shipments and follow up on delinquent shipments should be built in to the design.

The selection of biomeasure also is dictated by the perceived level of intrusion where blood draws are presumed to be most invasive and saliva the least, at least in the area of fluid biospecimens. In the Parsons et al. paper, and in the Smith et al. paper to a certain extent, tacit support for this notion is offered by the varied consent rates they observed for the various fluid draws. For example, Parsons and colleagues found observed consent rates in the 90% range for medical record, pathology report, and tissue reviews but that consent dropped to 76% for the blood draw. In the Smith et al. paper, consent rates were very high, with the exception of the vaginal swab, which was still a respectable 67%. This issue is discussed in greater depth in a later section of this paper.

Obtaining Consent

The issue of obtaining consent in the context of biomeasure collection is quite complex and multifaceted and likely warrants a session of its own at some future conference. Koenig covers many of these issues in her paper, and the book *Cells and Surveys: Should Biological Measures Be Included in Social Science Research?* (Finch, Vaupel, & Kinsella, 2000) provides in-depth coverage of the social and ethical issues of incorporating biomeasures into survey studies. The main issue here, as pointed out in the Smith et al. paper, is that most respondents are unfamiliar with the coupling of questionnaires and biomeasure collection. As such, what we know about consent in the classical survey data collection context may not be transferable to the realm of biomeasure collection. Due to the lack of regulation, how the collection is described to participants is not consistent. It can be described as DNA or genetic material, but also as a mouthwash sample buccal cell sample or saliva sample. This may, in turn, affect respondents' cooperation. Smith and colleagues found that a detailed description of the biospecimen collection in an advance letter brought about an onslaught of refusal calls. On the flip side, Parsons and colleagues argue for full disclosure in the consenting process. It is not clear whether IRBs will allow for less than full disclosure of all aspects of the biomeasure collection in this process, however. Furthermore, it is unclear if one's genetic material is "identifiable." While DNA is unique to a person, it is not clear that you can identify a person from their DNA—at least not at this time. DNA does not qualify as protected health information under HIPAA, so technically if other HIPAA identifiers are stripped, DNA is de-identified data. How does one convey such risk levels to lay respondents?

While a survey itself may have a relatively simple consent process, adding biomarker data adds new dimensions. Consent often is divided into multiple sections, where respondents can choose in which parts of the survey they want to participate. For the NHANES study described by Johnson and colleagues, certain biomarkers are grouped (e.g., environmental exposure), while some are specific (e.g., PSA test). This is the reason we see variable cooperation rates for different measures. Koenig describes a "tiered" consent process and access to biospecimens based on the number of Single Nucleotide Polymorphisms (SNPs) collected and/or made available whereby biospecimens collecting > 75 SNPs are rated high risk, < 20 SNPs intermediate risk, and no SNPs low risk. One of the goals of this approach is to provide adequate disclosure and education about the risk calculus of participation. Along these lines, future use of the data also needs to be explained—will the data be stored, and if so, for how long and what other tests will be performed? This is especially important with genetic data, where we may not know what types of analyses we can do in the future.

Another major issue is how and when to report the results of the biospecimen testing back to respondents. According to the Koenig paper, past practice in this area was to not report back any results lacking clear implications for the participant. However, it is not clear how good some of the emerging genetic/genomic tests are or whether they are appropriate for clinical use. Also, as the number of genetic tests increases, the chance of spurious findings increases. One of the major questions in this area is, are the obligations of survey researchers different than clinicians? Another question relates to a variant on Heisenberg's Uncertainty Principle, which states that one cannot observe a phenomenon without disturbing it. In this context, the act of collecting biomeasures, particularly information about genetic risks, may cause respondents to change their behavior if that information is filtered back to them. This would be particularly problematic in panel studies that require follow-up data collections.

Quality Control

Biomarker data also increases the potential for error. In addition to the usual sources of survey error, there is error associated with the collection and shipment of biological specimens and laboratory error. Errors in collection and shipment can come from incorrect recording of data by the interviewer or incorrect collection of the sample by the respondent. The Add Health study has tried to prepare for this by having blood pressure data keyed by the interviewers but also downloaded directly to the computer from the blood pressure cuff. Certain specimens have temperature constraints (must be frozen, cannot get too warm), and incorrect storage may destroy specimens. Table 3 offers a sampling of the different sources of error that are introduced with the addition of biomeasures to the survey data collection.

Table 3. Error Sources in the Collection of Survey-Based Biomeasure Data

Source	Examples
Survey respondent	• Failure/inability to attend study site • Failure to follow instructions (e.g., fasting) • Concerns about dispositions of specimens
Failure of the collection apparatus	• Equipment failure or damage in transportation • Loss of electrical power • Technician absence
Errors in specimen collection	• Failure to follow specific protocols • Mislabeling of containers • Breakage, loss, or mishandling of specimens
Mishandling in specimen transportation	• Failure to get specimen to lab in timely manner • Loss or breakage of containers • Microbial contamination or failure to store at correct temperature
Long-term specimen storage	• Loss, breakage, or contamination of specimens • Inadequate labeling/transcription
Laboratory determinations	• Lack of appropriate procedures • Inadequate quality control

The increase in error sources necessitates and underscores the importance of incorporating strict quality control mechanisms into the survey investigations. As both Johnson et al. and Ladner point out in their papers, the need for quality control

Source: Wallace (2000).

increases with the number of biomeasures collected. Johnson and colleagues enumerate the possible implications of low quality control where whole batches of NHANES data were rendered unusable because of contamination. Ladner offers a nice primer on how to plan for complex survey and biomeasure data collection that can serve as a model for others.

OUTSTANDING QUESTIONS/EMERGING RESEARCH AGENDA

A lot of the data collection practices associated with including biomeasures in surveys seem to be guided by clinical researchers and/or epidemiologists. The extent to which current practices in this area are informed by trained health survey research methodologists is not clear. One of the shortcomings in our current state of knowledge in survey-based biomeasure collection is the absence of methodological experimentation. This is not intended to be an indictment of the papers presented in this session but more a call to action on the part of health survey methodologists who have successfully embedded methodological experiments in large-scale studies in the past. Below, I list a number of methodological questions that remain unanswered. The purpose of listing these is to help shape future investigations in the realm of survey-based biomeasure data collection. The list is by no means exhaustive. For example, much work in the area of ethics and informed consent is needed but not highlighted below. In addition, weighty analytical issues, such as the reduction of the types of high-dimensionality data generated in genetic studies and the problem with extremely low incidence/prevalence of some conditions and the effect of that on sample size considerations, are not addressed in this section.

Question 1: How well does what we know about good survey data collection translate to the world of biomeasures?

- What is the effect of incentives, and how are they best utilized? Boyle and colleagues found some support for the notion that increasing incentives increases response, particularly splitting the $20 incentive so that the respondent gets $10 for the telephone interview and $10 more for the biospecimen.
- What is the effect of an advance letter? As mentioned earlier, Smith et al. received a number of call-in refusals when the advance letter for the NSHAP went out with detailed information on the biomeasure collection. Will an advance letter be as effective as it is in traditional surveys if one is required to mention the biomeasure collection at that point? What types of presentation techniques would be most effective? How should risk and scientific payoff be cast?

- How important are sponsorship and salience? Given that the collection of biomeasures involves invasive methods, like finger pricks, and the fact that some biospecimens may be stored well beyond the study period, how important is the trustworthiness and/or authority of the survey sponsor (both in terms of funding agency and data collection vendor)? A common method used in epidemiological studies utilizes case and controls. It has been historically more difficult to obtain response from controls than from cases, arguably due to salience, but the problem may be exacerbated by the inclusion of biomeasures. For example, in a recent Parkinson's study at Mayo Clinic that required an in-person interview and a blood draw, we attained an 85% participation from cases, 80% participation from controls who were blood relatives, and 56% from unrelated controls.

Question 2: Who does and does not respond to surveys that have a biomeasure collection component?

- Are nonrespondents like the types of nonrespondents typically seen in surveys that do not include biomeasures (e.g., young, male, non-White, childless, poorer health)? Parsons and colleagues observed some bias in consent rates among Latinas, older subjects, the more highly educated, and those with more advanced disease (at least in the case of consent to offer blood) in their breast cancer survey. Conversely, Boyle and colleagues found that even though less than half of respondents completing the telephone interview sent back saliva samples, there were few differences between respondents and nonrespondents sociodemographically and no difference in the key study outcome variables.
- Who is willing to supply survey data but not biomeasure data in the context of the same survey that includes the collection of both? In panel studies, what types of respondents are willing to participate in one survey but not the next?
- One option to advance understanding in this realm is to use a sampling frame that includes persons from whom biological data already are gathered so that a formal nonresponse bias analysis could be done that utilizes information that is closely aligned with the study topic. The Koenig presentation discusses the emerging biobanking initiatives across the country that could serve as such frames. Disease registries of all forms also could serve as sources of sample.

Question 3: Does response propensity vary by the type of specimen collected (e.g., blood vs. urine vs. saliva) or the purposes for which the specimen will be used?

- As mentioned earlier, consent rates varied by the type of biospecimen requested in the paper by Parsons and colleagues and the one authored by Smith et al., where blood draws brought the lowest consent rates in the former and vaginal swabs in the latter. In our own research at Mayo Clinic (Koka et al., 2007), where we surveyed over 400 outpatients, we found that the vast majority (97%) thought that blood was the most difficult to collect in the home, urine was the easiest, and saliva in-between. Also, if given a choice, the likelihood of these patients participating in a future research study was greatest if saliva was the specimen to be collected. This begs the question of *why* some respondents offer biospecimens while others do not. Is it concern over privacy, perceived burden, both, or neither?

- Does response propensity across specimen type vary by data collection site? Wallace (2000) indicates that specimens such as hair clippings, skin scrapings, cheek swabs, and rinses can be obtained with little difficulty by trained interviewers in the home but that other types of specimens such as tissue biopsies, multiple blood draws over the course of several hours, and complex physical tests are better collected in a clinical setting that has appropriate equipment and personnel.

Question 4: Of those who respond, are they more or less truthful in their responses in the presence of the biomeasure collection?

- In the literature dealing with the collection of self-reports of sensitive information, introducing a concept termed "the bogus pipeline" has been found to increase the veracity of self-reported information (Paulhus, 1991). The idea behind the bogus pipeline is that respondents are more truthful when they believe they are hooked up to a truth detector (the bogus pipeline) that could automatically detect lying. Does the collection of biological data increase the truthfulness of, say, substance abuse reporting?
- How do objective measures of physical function compare to self-reports of functional status in instruments such as the SF-36?
- Will we still see differences in the accuracy of self-reports across mode type (e.g., self-administered forms vs. interviews) and interview setting (e.g., in-home vs. clinic)?

CONCLUSION

As suggested by the trajectory of publications listed earlier in Figure 1, the issue of biomeasure collection in surveys is not going to go away any time soon. The papers in this session highlight the creativity and ingenuity survey researchers have used in addressing this increasingly important issue. Each paper was well written and informative and moves our understanding ahead. However, more work needs to be done before we can get to "best practices" in this area. It is only through the types of experimentation that brought the survey research field to this point that we can accrue the necessary understanding of the pluses and pitfalls of various approaches to biomeasure collection in surveys. It is also likely that the whole endeavor would benefit from cross-disciplinary training between biomedical and social scientists so that the former can learn more about survey methods and the latter about genetics and the like. With this increased understanding, science can fulfill the heretofore unrealized potential of all that survey-based biomeasure collection promises.

REFERENCES

Crimmins, E. M., & Seeman, T. (2000). Integrating biology into demographic research on health and aging (with a focus on the MacArthur Study of Successful Aging). In C. E. Finch, J. W. Vaupel, & K. Kinsella (Eds.), *Cells and surveys: Should biological measures be included in social science research?* (pp. 9–41). National Research Council Commission on Behavioral and Social Sciences and Education. Washington, D.C.: National Academy Press.

Finch, C. E., Vaupel, J. W., & Kinsella, K. (Eds.). (2000) *Cells and surveys: Should biological measures be included in social science research?* National Research Council Commission on Behavioral and Social Sciences and Education. Washington, D.C.: National Academy Press.

King, I. B., Satia Abouta, J., Thornquist, M. D., Bigler, J., Patterson, R. E., et al. (2002). Buccal cell DNA yield, quality, and collection costs: Comparison of methods for large-scale studies. *Cancer Epidemiology, Biomarkers & Prevention, 11*, 1130–1133.

Koka, S., Beebe, T. J., Merry, S. P., DeJesus, R. J., Berlanga, L. D., Weaver, A. L., et al. (2007). *Perception of saliva as a diagnostic fluid.* Manuscript submitted for publication.

Lum, A., & Marchand, L. (1998). A simple mouthwash method for obtaining genomic DNA in molecular epidemiologic studies. *Cancer Epidemiology, Biomarkers & Prevention, 7*, 719–724.

Paulhus, D. L. (1991). Measurement and control of response bias. In J. P. Robinson, P. Shaver, & L. S. Wrightsman (Eds.), *Measures of personality and social psychological attitudes* (pp. 17–59). San Diego: Academic Press.

Roese, N. J., & Jamieson, D. W. (1993). Twenty years of bogus pipeline research: A critical review and meta-analysis. *Psychological Bulletin, 114*, 363–375.

Wallace, R. B. (2000). Applying genetic study designs to social and behavioral population surveys. In C. E. Finch, J. W. Vaupel, & K. Kinsella (Eds.), *Cells and surveys: Should biological measures be included in social science research?* (pp. 229–249). National Research Council Commission on Behavioral and Social Sciences and Education. Washington, D.C.: National Academy Press.

Weinstein, M., & Willis, R. J. (2000). Stretching social surveys to include bioindicators: Possibilities for the Health and Retirement Study, experience from the Taiwan Study of the Elderly. In C. E. Finch, J. W. Vaupel, & K. Kinsella (Eds.), *Cells and surveys: Should biological measures be included in social science research?* (pp. 250–275). National Research Council Commission on Behavioral and Social Sciences and Education. Washington, D.C.: National Academy Press.

FEATURE PAPER: Operational Issues of Collecting Biomeasures in the Survey Context

Stephen Smith, Angela Jaszczak, and Katie Lundeen, *NORC at the University of Chicago*

BACKGROUND

This paper focuses on the operational challenges and considerations for collecting biomeasures using nonmedical staff and draws heavily from recent experience with the National Social Life, Health, and Aging Project,[Note 1] and some sections of the paper are excerpted from a manuscript by the authors currently under peer review (Jaszczak, Lundeen, & Smith, 2007).

Biomarkers have a specific medical definition: "a distinctive biological or biologically derived indicator (as a biochemical metabolite in the body) of a process, event, or condition (as aging, disease, or exposure to a toxic substance)."[Note 2] The medical literature often refers to the assay generated from a specimen—such as blood—as the biomarker; for example, blood assays of albumin and cholesterol are biomarkers of cardiovascular health. But in the survey context where a broad range of measures may be collected, these may not be strictly "markers" but perhaps are more accurately labeled as biomeasures. This paper will use the word "biomeasures" to better reflect the looser definition used by health survey researchers.

Biomeasures have been collected in conjunction with survey data for many years. Depending on the specific requirements of the study, including type of biomeasure, cost, other resource constraints, and demographics of the study population, biomeasures and survey data can be collected from participants by employing one or more data collection models. At one end of the spectrum—in terms of cost, range of biomeasures, and quality of data—is the centralized collection of biomeasures at a medical facility. In this case, study participants might be asked to visit a hospital, clinic, or specialist's office to complete one or more biomeasures. The questionnaire can be either administered during these visits or collected at another time. A variation of this model that retains many of the benefits of using high-quality facilities, equipment, and trained medical staff is the use of mobile clinics that can be moved from location to location. A prime example is the National Health and Nutrition Examination Survey (NHANES).[Note 3]

At the other end of the spectrum is self-administered biomeasures collected using equipment that is mailed or left with the respondent. This method can be very cost effective but is limited by the range and complexity of biomeasures that can be collected: some equipment may not be suitable for mailing or handling by the survey respondent, or the correct administration of the biomeasure protocol may require training beyond what can be provided to the participant in simple written instructions. In addition, quality control of the specimen collection and shipping can be problematic (i.e., was the collection protocol followed correctly and has it been handled and shipped as instructed?).

More recently, the development of robust, portable, reliable, and easy-to-use equipment has made a wider range of in-home biomeasure collection feasible on larger samples using nonmedically trained researchers and field interviewers.[Note 4],[Note 5] Protocols and equipment are available for field interviewers to collect an already extensive and growing range of biomeasures. Some examples include the following:

- Height, weight, waist, hip circumference, and other body size measurements
- Blood pressure, pulse rate
- Blood spots, glucose tests
- Smell
- Taste
- Sight
- Touch
- Hearing
- Chair stands, timed walk, get up and go
- Urine
- Hair
- Oral mucosal transudate (OMT)
- Lung function (peak flow)
- Buccal swabs
- Vaginal swabs
- Saliva
- Grip strength

Using traditional field interviewers to collect biomeasures opens the door to many studies that previously did not have the resources required to send specialists (such as phlebotomists or medical technicians) to a respondent's home or for respondents to visit a centralized location for the collection of the biomeasures. The use of field interviewers provides an opportunity to cost effectively and efficiently capture biomeasure data from nationally representative populations and can overcome difficulties (such as respondents' immobility due to poor health, lack of transport, or remoteness) to gain the participation of population subgroups that might otherwise be missing or underrepresented in the study population.

Given that using biomeasures in the survey context is a relatively new tool for health researchers, the literature in this area is limited but growing.

NSHAP OVERVIEW

NSHAP is an innovative study of older adults that examines the interaction between aging, social relationships, and health outcomes. Between July 2005 and March 2006, NORC field staff completed 3,005 two-hour in-person interviews with a nationally representative sample of community-residing adults age 57–85. Most respondents received $100 in cash for their participation, but this was increased in the closing weeks of the field period to help convert reluctant and hard refusal cases. The weighted response rate using AAPOR (2006) RR2 was 75.5%.

The NSHAP interview contained three distinct components: (1) a detailed in-person questionnaire focused on physical, mental, and sexual health and social networks; (2) the collection of 13 biomeasures (height, weight, waist, touch, smell, vision, taste, blood pressure, blood spots, saliva, Orasure® HIV test, vaginal swabs, and "get up and go") administered by a NORC field interviewer; and (3) a post-interview mail questionnaire to collect additional survey data to supplement the in-home interview. Although some of these biomeasures have been collected in other national and community-based studies, the number and range of the biomeasures collected in NSHAP make the study rather unique.

Table 1. NSHAP Preliminary Biomeasure Cooperation Rates

Measure	Cooperation Rate	Eligible Respondents
Height	98.6%	2,977
Touch	98.4%	1,505
Weight	98.4%	2,977
Blood pressure	98.4%	3,004
Smell	98.3%	3,003
Waist	97.2%	3,004
Distance vision	96.0%	1,505
Taste	95.9%	3,004
Get up and go	93.6%	1,485
Saliva	90.8%	3,004
Oral fluid for HIV	89.2%	972
Blood spots	85.0%	2,494
Vaginal swabs	67.5%	1,550

As shown in Table 1, the cooperation rates in the biomeasure collection were generally quite high, with 10 of the 13 measures achieving cooperation rates in excess of 90%—8 of the 10 rates were greater than 95%. Not surprisingly, given the more invasive nature of the test and the physical challenge for some women to perform the test, the request for self-administered vaginal swabs had the lowest but still very respectable cooperation rate of 67.5%.

LESSONS LEARNED & OTHER CONSIDERATIONS

Below we describe some of the operational challenges to be considered during the study design stage and lessons learned from the NSHAP experience.

Biomeasure Equipment

One of the most significant limiting constraints on the type of biomeasures that can be successfully collected by field interviewers is the biomeasure collection equipment. To meet the demands of life in the field, the equipment needs to satisfy a number of criteria:

1. **Quality.** The equipment must produce consistent and accurate measures. Ideally, it should produce measurements or collect samples that are as close as possible to those produced in the "gold standard" conditions of a medical facility or laboratory.
2. **Portability/weight.** Field interviewers need to be able to transport the equipment from location to location, which can mean carrying the equipment from their car to the respondent's home, having to carry it up several floors, and sometimes traveling by plane. Consequently, the equipment needs to be either small or easily assembled and modest in weight. The NSHAP interviewers were provided with inexpensive airplane-style wheelie cases to protect and transport all of their equipment and supplies.
3. **Robustness.** All field equipment from paper documents to laptops and other sensitive equipment is subject to wear and tear from transit and unpacking and packing at each interview location, with some field interviewers completing in excess of 100 interviews during the course of the field period. Thus, the biomeasure equipment needs to be sufficiently robust to withstand the rigors of life on the road.
4. **Cost.** As with many other types of specialist equipment, the combination of quality, light weight, and robustness usually comes at a premium price. Fortunately, public demand for good quality health devices and supplies that can be used at home has resulted in the availability of a wide range of equipment at reasonable prices. NSHAP and other large studies have the potential to negotiate volume discounts, but the items used often are available relatively inexpensively in drug and medical supply stores and via suppliers on the Internet.

Interviewer Recruitment

Given the comprehensive set of biomeasures that we planned to collect on NSHAP, we attempted to recruit interviewers for the pretest that had a background in the health service industry. For the NSHAP pretest, interviewers came from varied backgrounds, such as social workers, nurses, physicians, phlebotomists, and interviewers with experience on other health studies (some of which had included biomeasure collection). We assumed that their confidence with collecting biomeasure data would instill more confidence in respondents and result in higher cooperation rates. However, we learned that these skills were useless if they were unable to secure respondent cooperation at the doorstep. Although we did not conduct a formal experiment in the pretest to compare the reasons for refusal by interviewer characteristics, we could see that more experienced interviewers were far more effective at gaining cooperation than those who had good biomeasure experience but less of an interviewing background.

Based on the experience from our small pretest, we opted for the main data collection to seek more experienced field interviewers who had the requisite communication and persuasive skills to win the trust of respondents or gatekeepers. We have come to the conclusion that in the context of household-based surveys, it is generally better to train traditional field interviewers how to collect biomeasures than recruit and train those with a medical-oriented background how to conduct interviews.

Field interviewers need to be comfortable with and willing to collect biomeasures; this necessitates a thorough screening of candidates before hiring them for a study. On NSHAP, we screened both experienced and newly hired interviewers. Candidates were screened and provided with clear expectations about the interviewer's duties on the project. We focused most of our efforts on the biomeasure expectations by outlining the measures they were expected to collect and the shipping and storage expectations for the laboratory samples. In some cases, such as for weight and blood pressure collection, a written or verbal explanation of the measures was sufficient. For other measures, additional detail was necessary to provide a clearer picture of interviewer duties. For example, candidates were provided with a pictorial outline of the key steps in the blood spot protocol to make it clear they would be pricking the respondent's finger and placing blood spots on collection paper. Another example is sharing with interviewers the expectation that saliva samples would be stored in their freezers until the designated shipping date. This was illustrated by showing candidates pictures of the saliva storage box inside a freezer and providing them with the dimensions of the storage box.

Interviewer gender also can be an important consideration during the recruitment of field staff. Recruitment decisions might be influenced by the type of biomeasures to be collected, such as waist and hip circumference, which require a degree of physical contact between the interviewer and the respondent, or the requirement to discuss with the respondent the correct method for the self-collection of specimens such as vaginal swabs or urine; and sensitivity to the location of the interview, such as the likelihood that only the respondent and the interviewer may be present in the respondent's home.

Interviewer Training & Training Materials

The importance of interviewer training is critical to the success of the biomeasure collection. Unfortunately, this paper cannot provide in the space permitted a detailed discussion of this activity but can only highlight some of the most critical elements that should be considered during the development and conduct of the study's field staff training.

NSHAP instituted a multidimensional approach to train individuals to collect biomeasures that included a home study package, in-person training, and booster trainings during data collection.

Home Study Package

A home study package was sent to all hired interviewers before they arrived at the in-person training. It contained a field manual, video, and homework assignment. The manual provided an overview of the biomeasure collection and contained step-by-step collection instructions with photos to illustrate the process.

Interviewers also were required to watch a training video before arriving at in-person training. The video was created specifically for NSHAP training purposes and depicted a scripted interview that focused on biomeasure collection during the interview. The interview was filmed and shown in real-time so the viewers would observe the interviewer explaining the measure to the respondent, interacting with the respondent during the measure, entering data into the computer, and transitioning to the next measure. A separate segment of the video instructed interviewers on how to ship the specimens to the corresponding laboratories. Interviewers were not expected to learn all the collection procedures through the video; instead, its purpose was to give the interviewers an overview of the collection process and show them how to smoothly transition from one measure to the next.

Although the primary purpose of the home study package was training, it also served as a final stage of the screening process. The video in particular gave interviewers a clear picture of their tasks regarding biomeasure collection and shipping.

In-Person Training

Over the summer of 2005, three training sessions were conducted to train 130 field interviewers to administer the NSHAP questionnaire and biomeasures. The in-person training comprised four days of NSHAP-specific instruction divided between two project training days of active lectures—each focusing on field operations and administering the questionnaire or collecting the biomeasures, a self-study day, and lastly, a certification day.

Active lecture

Project training on biomeasure collection employed an active lecture format to train interviewers to collect each of the 13 biomeasures. A consistent format was followed for each measure: the trainer would explain the collection procedure ("tell"), the trainer would demonstrate the collection procedure ("show"), and then the trainee would practice the collection procedure ("do"). For the "tell" step, the trainer described the collection steps and emphasized important details using PowerPoint slides as a visual aid. During the "show" step, the trainer would play the role of the interviewer, and the assistant trainer would play the role of the respondent. The "do" step had the trainees perform the biomeasure collection steps with a partner. The biomeasure training day also included a special session on safety and universal precautions when collecting biomeasures.

Self-study

To enforce consistent collection of the methods learned during the active lecture day, practice sessions were built into the training that included participation in mock interviews and appointments with trainers. Throughout the self-study day, interviewers rotated through a series of modules focused on providing them with ample opportunities for practice. During the mock interviews, field interviewers were matched up with a partner and required to perform dry runs of the entire interview. These mock interviews provided the interviewers with an opportunity to both put all the pieces of the interview together and continue practicing the biomeasure collection procedures. It also provided the pair a chance to role-play the respondent, increasing awareness of how it feels to be a respondent. Feedback received from their peers in these sessions helped interviewers focus on areas for improvement.

The self-study day also was designed to provide interviewers with small group and individual assistance from the trainers. Throughout the training, we prioritized opportunities for individual feedback and time to ask questions. In one session, two interviewers were paired with a trainer for a biomeasure practice session where the interviewers could request additional help with specific measures. In another module dedicated specifically to blood spot collection, interviewers could work directly with trainers and staff from one of the laboratories to improve their collection techniques.

Certification & pre-field practice

To ensure that every interviewer who completed training correctly followed collection protocols and was comfortable obtaining samples, each interviewer was individually certified by a trainer. Before being allowed to begin data collection, interviewers also were instructed to recruit a friend or family member and conduct a final run-through of the entire in-home interview. Conducting this mock interview outside of the training environment provided interviewers with an opportunity to practice the interview with someone not familiar with the project and with additional time to process the information from training before completing their first cases.

Booster Training

An additional training component used during the NSHAP field period was "booster trainings"—brief training sessions that occurred after the interviewer returned home and began data collection. The purpose of these trainings was to reinforce specific aspects of in-person training and provide additional training on new issues encountered in the field through e-mails, visual aids (e.g., pictures or examples of correctly filled-out laboratory paperwork), feedback from field managers, and group phone calls. Group phone calls were particularly helpful, as they provided an opportunity for interviewers to both ask questions of their peers and provide helpful advice and examples of techniques that were working for them in the field.

Placement of Biomeasures in the Interview

Our first thoughts on where best to place the biomeasures changed significantly based on experience from the pretest. Initially we viewed the collection of biomeasures as an activity for the field interviewers and respondents that is significantly different than standard questionnaire administration. NSHAP was collecting a rather extensive array of biomeasures, so for the pretest, we broke the biomeasures into three blocks that were carefully inserted into the questionnaire at natural transition points. At that time, we believed the change from questionnaire to biomeasures would retain respondent interest by changing the activity and break up a relatively lengthy interview. However, we learned that these transitions from questions to biomeasures and back again were very time consuming and disrupted the general flow of the interview. We followed the advice of the interviewers for the main data collection and moved the biomeasures into a single block, which both shortened and greatly improved the flow of the interview.

Specimen Shipping Challenges

Some biomeasures, such as weight, height, mobility, and grip strength, are completed fully at the time of the interview and do not require any additional interviewer action. But some biomeasures—often those that require the collection of specimens, such as saliva, urine, blood spots, cheek swabs, and vaginal swabs—can require very specific storage and shipping procedures to get the specimens from the respondent's home to the laboratory. This can include storing and shipping specimens in special containers with ice packs, dry ice, or specially marked biohazard containers.

Specimens such as saliva may need to be shipped on dry ice, which requires additional training and gloves for the interviewers to handle it safely. Dry ice is available only at limited locations, so identifying sources close to interviewers' homes or hotels (if traveling to complete interviews) is required in advance of field work. Field staff also need to be cognizant of when laboratories are open and able to accept incoming specimens—e.g., specimens can be spoiled if shipped on Friday and not unpacked until the laboratory opens on Monday.

Amount of Information to Give Respondents in the Advance Letter

Respondents generally are well versed in the administration of surveys and know what to expect; they are not so familiar with surveys that combine a questionnaire with biomeasures. Consequently, researchers are faced with a relatively new challenge of how much information about the biomeasures to disclose to the respondent prior to the interview. So a balance must be sought between meeting IRB requirements for full disclosure and providing sufficient information about what to expect during the interview that avoids respondents being overwhelmed by what is in store for them.

Our experience on the NSHAP pretest completely changed our opinion of how much information to provide those sampled for the study. We began the pretest with the expectation that respondents would be interested in knowing all about the biomeasures, such as what the interviewer would collect, what equipment would be used, and what results would be made available. However, refusal calls to the project toll-free line and feedback from interviewers soon indicated that this was not the most effective approach. So we used a simpler and less detailed advance letter for the main study and relied on interviewers to discuss the study directly with the respondent and address any questions or concerns raised at that time.

Protection of Human Subjects

The inclusion of biomeasures in survey research presents researchers and Institutional Review Boards (IRBs) with new challenges for protecting human subjects. As with most submissions of survey protocols to IRBs, the consent form is arguably one of the most important and carefully reviewed documents. At a minimum, the consent form should address the rationale for and knowledge to be gained by including biomeasures, the collection procedures to which respondents will be subjected, the potential benefits to respondents and society, and the potential risks to respondents and precautions to minimize those risks. In addition, given the technical and medical terminology that often describes biomeasures, special attention should be paid to drafting an informed consent statement in simple understandable language that fully informs subjects about what measures they will be asked to provide and for what conditions their samples will be tested. A discussion of whether the research team has a plan to provide respondents with their results (and which results) also should be addressed.

Laboratory technology is continually advancing, which can lead to new assays becoming available that were not included in the original research protocol. Therefore, researchers should consider if the consent form should address whether the samples provided by respondents will be discarded or stored for future use, and if stored, for how long and for which tests they may be used.

Medical Malpractice Insurance

Organizations that do not usually collect biomeasures or handle biospecimens should consider securing medical malpractice insurance, although this can be quite expensive for relatively modest coverage. We learned that our standard insurance covering usual interviewer activities did not provide coverage for some of the biomeasures—those that required handling biospecimens (such as blood, urine, and saliva samples) appeared to be of most concern to the insurance carrier. As is usual practice with this type of risk, we opted for coverage during the data collection period and "tail-end" insurance for several months after the close of the field period.

REFERENCES

American Association for Public Opinion Research. (2006). *Standard definitions: Final dispositions of case codes and outcome rates for surveys* (4th ed.). Lenexa, KS: Author.

Jaszczak, A., Lundeen, K., & Smith, S. (2007). *Using non-medically trained interviewers to collect biomeasures in a national in-home survey.* Manuscript submitted for publication.

[Note 1] NSHAP is supported by NIH—National Institute on Aging, Office of Women's Health Research, and Office of AIDS Research (5R01AG021487). NSHAP is directed by Linda J. Waite, Principal Investigator, and Co-investigators

Edward Laumann, Wendy Levinson, Stacy Tessler Lindau, and Colm O'Muircheartaigh.

[Note 2] *Merriam-Webster Online Medical Dictionary*: www.merriam-webster.com

[Note 3] www.cdc.gov/nchs/nhanes

[Note 4] 2004 Health and Retirement Survey (HRS) used field interviewers to conduct a breathing test (peak flow), grip strength, timed walk, height, and weight. http://hrsonline.isr.umich.edu/meta/2004/core/desc/h04dd.pdf

[Note 5] Wave III of the National Longitudinal Study of Adolescent Health (AddHealth) collected oral mucosal transudate (OMT), urine, saliva, weight, and height.

www.cpc.unc.edu/projects/addhealth/files/biomark.pdf

www.cpc.unc.edu/projects/addhealth/codebooks/wave3

FEATURE PAPER: Biological Specimen Collection in an RDD Telephone Survey: 2004 Florida Hurricanes Gene and Environment Study

John M. Boyle, *Schulman, Ronca & Bucuvalas, Inc.*
Dean Kilpatrick, Ron Acinerno, Kenneth Ruggiero, and Heidi Resnick,*Medical University of South Carolina*
Sandro Galea, *University of Michigan*
Karestan Koenen, *Harvard University*
Joel Gelernter, *Yale University*

INTRODUCTION

The 2004 Florida Hurricanes Gene and Environment Study investigated gene and environment interaction to gain a better understanding of why exposure to the same environmental risk has different effects. Specifically, the study sought to replicate findings from a 2003 study (Caspi et al.) for a gene and environment interaction for major depression in the context of an epidemiological survey by telephone following a natural disaster. Additionally, the project sought to determine whether the gene and environment interaction for major depression could be extended to posttraumatic stress disorder.

One of the objectives of the study was to determine whether it was possible to expand epidemiological data collection to include biological samples for genetic analysis from a telephone survey of a community population. Self-administered specimen collection by respondents after a telephone interview with community samples drawn by random-digit-dialing rarely have been reported in the literature. However, the value of this technique for trauma research in particular and health research in general could be quite high, if successful.

The study design included the collection of saliva samples for genetic analyses using pre-assembled collection kits. During the first phase of this project, three different protocols were tested in the recruitment of respondents who completed the telephone interview for the saliva collection. The most productive of the three techniques was adopted for the remainder of the sample.

METHODS

The RDD survey was conducted among 1,543 households in Florida counties directly affected by the 2004 hurricanes. Since natural disasters more profoundly affect older individuals who may have fewer resources to recover from a disaster, persons age 60 and older were sampled disproportionately (*N* = 1,130) compared to persons age 18–59 (*N* = 413) in these areas.

The exposure to each of these four hurricanes, including being present during hurricane winds, significant property damage, loss of two or more basic utilities, and being displaced from home for more than one week, was assessed for each respondent. The potential psychological outcomes associated with trauma included posttraumatic stress disorder (PTSD), major depression, and generalized anxiety disorder (GAD). The interview also included measures of social support as well as general demographics.

The telephone interviews, which averaged 25 minutes in length, were conducted between April 5, 2005, and June 12, 2005, by Schulman, Ronca and Bucuvalas, Inc. (SRBI). Since the study design called for heavily oversampling older adults, a five-attempt protocol was adopted as more cost-efficient for screening purposes. Extended contact protocols are more useful when trying to sample younger respondents.

The collection kit, which was mailed to respondents after completion of the telephone interview, included a small bottle of Scope mouthwash, a 50 ml collection tube with a 10 ml mark, a set of instructions, and return mail materials. Instructions told participants to pour the mouthwash into the tube up to the mark, place contents of the tube into the mouth and swish orally 10 to 20 times, spit it back into the tube, place the stopper on the tube, place the tube in the return mail package, and express mail it to the designated laboratory using the prepaid mailing label.

RECRUITMENT FOR SPECIMEN COLLECTION

According to the study protocol, once the respondent had completed the telephone interview, he or she was told that we would like to obtain a saliva sample from study participants. Respondents who were interviewed on the first two nights of data collection were offered a check for $10 if they would provide a sample and return the kit. This protocol was followed for 49 interviews conducted on April 5 and April 6. Sixty-one percent of the 49 cases in the first protocol group agreed to participate in the specimen collection phase of the study. Ultimately, 14 specimens were received from this group. This represents less than three in ten (28.6%) of the first sample and less than half (46.7%) of those who agreed to provide a buccal cell specimen at the end of the interview.

A second protocol was introduced on April 8, which increased the incentive for completing and returning the specimen kit to $20. This approach was followed for interviews conducted on April 8 through April 11. A total of 51 interviews were completed under the second protocol. Approximately the same proportion of respondents in the second group agreed to receive the specimen kits. However, usable specimen samples ultimately were received from 19 of the 51 respondents (37.3%) who were offered the $20 incentive to return the specimens.

The lack of improvement in the proportion of respondents who agreed to participate in the specimen collection phase under the second protocol led the research team to introduce a third protocol. The new procedure was to offer all survey respondents $10 to conduct the 25-minute telephone interview. At the completion of the interview, names and addresses were collected from those who participated in the survey. The survey participants who provided name and address information were mailed a $10 check for their survey participation along with an invitation to participate in the specimen collection phase of the project, for which they would receive another $10. The invitation package included a detailed explanation of the rationale for the specimen collection, as well as the specimen collection kit and instructions for its use. They also were provided a toll-free number to answer questions about the study or the specimen collection procedures. Fifty interviews were conducted on April 13 and April 14 under the third protocol. Specimens were obtained from 25 out of the 50 respondents (50%) under the third protocol.

As it yielded the highest return rate for biological specimens, the third protocol was adopted for the remainder of the study. Interviewing resumed on May 18. A total of 1,393 respondents were interviewed in this fourth group between May 18 and June 12. A total of 579 persons in the fourth group eventually returned a specimen (41.6%). When these cases were combined with the initial 50 cases in the third test group, then the third protocol produced a 41.9% return rate of biological specimens.

It was apparent within a few weeks after the application of the third protocol for the remainder of the survey that the return rate was lower than the rate achieved during the experimental phase of the third protocol. The difference between the return rates in the experimental and follow-up phases of the third protocol were not statistically significant. There is no obvious difference in the characteristics of individuals in the experimental and follow-up phases of the third protocol that would explain the difference as more than sampling variability.

Ultimately, usable specimens were obtained by these procedures from 625 of the 1,543 respondents from the community sample who participated in the telephone interview (40.6%). Twelve specimen kits were received in unusable condition (0.6%). In most cases, there was either a leak in the specimen tube or the respondent had failed to use the mouthwash. In one case, the respondent had provided the wrong biological specimen. Since 98% of those who returned the specimen kits provided usable specimens, the remainder of this analysis will be based on the 637 respondents who did return a specimen kit, regardless of whether it was usable.

HURRICANE & OTHER TRAUMA EXPOSURE

Less than half of a random sample of adults in Florida counties affected by the 2004 hurricanes provided spit samples for the evaluation of the gene-environment interaction hypothesis. The key question, then, was whether those who provided samples were different from those who did not. Hence, we have compared the characteristics of the 625 cases from which a usable sample was obtained and the 918 cases for which it was not.

In most surveys, the salience of the subject matter is a major factor in participation rate. This is particularly true in self-administered surveys where the researchers have little control over respondent participation. Hence, the first critical question is whether those persons who were more exposed to the hurricanes were also more likely to participate in the specimen collection.

The proportion of survey respondents who reported they had to evacuate from the place they were living because of any of the storms was virtually identical for those who returned the specimens (33.4%) and those who did not (34.3%). Similarly, the proportion of respondents who reported they were personally present when hurricane force winds or major flooding occurred because of the storms was identical for those who returned the specimens (83.6%) and those who did not (83.6%). The proportion of respondents who reported storm damage to the place they were living or other personal property loss was very similar for those who did (57.5%) and did not (59.5%) return the specimen. Among those who reported any storm damage, the proportions who reported that the damage was severe enough that they were unable to live in their home was virtually identical for those who returned the specimen (14.2%) and those who did not (13.9%).

The proportion of survey respondents who reported they were without electricity, without telephone service, without adequate water, and without food as a result of the hurricanes was generally identical for those who returned specimens (84.3%, 53.9%, 17.4%, and 6.9%, respectively) and those who did not (83.4%, 56.3%, 15.9%, and 9.6%, respectively). The proportion who said they were without adequate clothing as a result of the storm was the same for those who did (2.7%) and those who did not (2.7%) return specimens. There was also no significant difference between those who returned the specimens and those who did not in the loss of crops (50.9% vs. 53.0%), furniture (17.4% vs. 16.4%), automobiles or trucks (4.7% vs. 6.8%), sentimental possessions (4.4% vs. 4.1%), or pets (1.3% vs. 1.0%). The proportion of survey respondents who suffered total losses of less than $1,000 from the hurricanes was identical for those who returned the specimens (40.7%) and those who did not (40.8%).

One of the key elements of trauma, particularly as it relates to PTSD, is fear. Survey respondents were asked how afraid they were during the hurricane that they might be killed or seriously injured by the storm. There was no appreciable difference between those who returned the specimens and those who did not in feeling not at all afraid (35.8% vs. 34.8%), a little afraid (22.9% vs. 23.9%) or moderately to extremely afraid (41.3% vs. 41.3%). Hence, there appears to be no evidence of self-selection in the return of specimens among those who experienced more storm damage, experienced more privation during the hurricanes, or felt more threatened by the storms.

One of the risk factors for PTSD after traumatic events is a history of prior exposures to traumatic events. Thus, if there was a difference between the two groups in lifetime experience of traumatic events, it could produce a difference in PTSD between the two groups even if the rate of trauma from the hurricanes was about the same. However, we found no significant difference between those who did and did not return specimens in their lifetime experience with natural disasters (48.7% vs. 49.9%), having had a serious accident at work (30.8% vs. 31.5%), having been attacked with a gun (13.7% vs. 12.8%) or without a weapon (11.2% vs. 11.5%), or having been in military combat or a war zone (14.9% vs. 12.3%).

HEALTH & MENTAL HEALTH OUTCOMES

The outcome variables for the survey were post-traumatic stress disorder, major depression, and generalized anxiety disorder. The rate of current PTSD in the sample was 3.0%. The proportion of respondents who returned a saliva sample was identical (41%) for those respondents who met criteria for current PTSD and those who did not.

The proportion of telephone survey respondents who met criteria for major depression was 4.9%. Those meeting those criteria were somewhat more likely to return the saliva kit (47%) than those who did not (41%). However, the difference was not statistically significant.

Six percent of respondents met GAD criteria and were somewhat more likely to return the saliva kit (45%) than those who did not meet the criteria (41%). However, like the other mental health outcomes, the difference in return rates was not statistically significant.

Social support was expected to be an intervening factor between trauma exposure and mental health outcomes. Social support was measured using the Medical Outcomes Study questionnaire. There was no statistically significant difference between those respondents classified as low on social support (43%) and those who were classified as high (41%) in the rate of return of specimen kits.

In the absence of any significant difference in the degree of exposure to trauma or social support between those who returned specimens and those who did not, it should not be surprising that there was no significant difference in the mental health outcomes between the two groups. Although this was the key issue for this project, difference in rate of return by physical health status has broader implications for the use of self-administered specimen collection for community-based health surveys.

The general self-health rating question is recognized as the best single predictor of health status. The proportion of respondents who returned the specimen kits was essentially the same for those who rated their health as excellent (42.5%), very good (41.7%), good (43.5%), and poor (41.5%). Somewhat fewer (34.5%) of those who rated their health as “fair” returned the kits, but the difference is not statistically significant. Hence, there is no evidence of bias by health status in the DNA specimens from a community sample collected by this process.

DEMOGRAPHIC DIFFERENCES

Saliva collection in the Agricultural Health Study (Engel et al., 2002) was conducted among an exclusively male subsample, so gender differences in return rates for saliva specimens could not be assessed. In the National Smoking Survey (Kozlowski et al., 2002), the proportion of males who returned the saliva kit (41%) was essentially the same as the proportion who completed a telephone interview (39%). In the Florida Hurricane Survey, there was no significant difference between male (41.7%) and female (41.4%) respondents in their rate of return of saliva kits.

Although incentives frequently are reported as being more effective among lower-income populations, there is little evidence that these respondents were more likely to provide specimens in return for the incentives tested. The proportion of survey respondents who returned the specimen kits was 44.8% for those with incomes under $5,000, 39.0%–39.1% for those with incomes between $5,000 and $15,000, 39.7%–50.5% for those with incomes between $15,000 and $35,000, 44.1%–46.2% for those with incomes between $35,000 and $100,000, and 35.0% for those with incomes over $100,000. In short, there was no statistically significant difference in the rate of specimen return by income.

Both the Agricultural Health Study (in Iowa, but not North Carolina) and the National Smoking Survey found that older respondents were more likely to return their buccal specimens than younger respondents. The Florida Hurricane Survey found that the rate of specimen return increased from 32.0% among those age 18–39 to 35.7% among those age 40–59 to 44.3% of those age 60 and older. These differences are statistically significant.

There was also a substantial difference in minority status between those who returned the specimens and those who did not in the Florida Hurricane Survey. Among those who classified themselves as White, 43.5% returned the specimens compared to 27.3% of those who classified themselves as something other than White. Similarly, only 28.8% of those who considered themselves to be Hispanic returned specimens, compared to 42.2% of those who did not. The differences in specimen return rates by race (White/non-White) and ethnicity (Hispanic/non-Hispanic) are statistically significant. In the North Carolina sample of the Agricultural Health Study, those who returned specimens were more likely to be White. In the National Smoking Survey, Whites were more likely to return specimens, while Hispanics were less likely to return them than non-Hispanics.

The Florida Hurricane Survey found a demographic bias in the age, race, and ethnicity in a community-based telephone survey between those who return a saliva collection kit and those who do not. It should be noted that in the Florida sample, there is a correlation between age and race/ethnicity, since the younger respondents are more likely to be non-White and Hispanic. However, the findings suggest that minority status and age interact in the likelihood of survey respondents participating in specimen collection. Among persons under age 40, non-Whites were more likely (38.9%) than Whites (30.2%) to return the specimen kits. Among those persons age 40–59, non-Whites were about as likely (34.6%) as Whites (35.6%) to return the kits. It was only among those persons age 60 and older that non-Whites were substantially less likely (21.2%) than Whites (47.1%) to return the kits.

A similar pattern was found in the specimen return rate by ethnicity. Among persons under age 40, Hispanics were more likely (36.8%) than non-Hispanics (31.0%) to return the specimen kits. Among those persons age 40–59, Hispanics were still more likely (46.2%) than non-Hispanics (35.2%) to return the kits. It was only among those persons age 60 and older that Hispanics were substantially less likely (21.3%) than non-Hispanics (45.7%) to return the kits.

DISCUSSION

The Florida Hurricane Survey demonstrates that DNA can be collected successfully by buccal cell rinse collection among a large subsample of respondents in a community RDD survey. The rate of returns of specimens in the Florida Hurricane Survey was 41%, which is intermediate for the three samples reported in the literature—26%, 42%, and 68%. It should be noted, however, that the Florida study oversampled persons age 60 and older, who are more likely to return saliva samples. In using the Florida data to predict return rates for other community-based telephone surveys, the sample would have to be weighted back to the expected population distribution for those studies.

Our findings suggest that DNA data collection from a RDD sample of households following a telephone interview is an appropriate method for trauma research. There were no statistically significant differences in trauma exposure, social support, or mental health outcome measures between those who participated in the second phase of specimen collection and those who did not. When this is coupled with the ability to collect both interviews and specimens from a community sample in a rapid manner after a disaster, the value of the approach is demonstrable.

The Florida Survey also found no statistically significant difference in the health status of those who do and do not provide biological specimens, suggesting that the technique may have broader applications to health research more generally. The lack of statistically significant differences between participants and nonparticipants in gender and income are also encouraging for broader applications of self-administered specimen collection among community samples after telephone interviews.

Nonetheless, this study confirms the findings of earlier studies that younger respondents and minorities are less likely to participate in specimen collection after a telephone interview. While there are a number of possible explanations, including problems of mail delivery in central cities and multifamily dwelling units, less familiarity with medical testing, and greater concerns about the uses of the tests, these are not testable with this data. At minimum, researchers should be aware that specimen collection will be less successful among younger and minority respondents recruited via telephone.

The approach to soliciting biological specimens among a telephone survey sample appears to affect the return rate, although the samples used for our experiments were small. Not surprisingly, the larger incentive ($20) produced a better response rate. Sending the kit with a written explanation and instructions appears to produce a higher return rate for what is actually a smaller incentive for specimen return ($10). However, the total cost of the third option is substantially higher than the second alternative.

Ultimately, we believe that genetic research will play a critical role in realizing the potential of health surveys. The findings presented in this paper demonstrate that DNA can be collected in a rapid and relatively cost-efficient manner among a large subsample of a community-based household sample. Since there is no bias by health or mental health status in regards to respondents who provided a buccal cell specimen, we believe that saliva collection should be incorporated into health surveys by telephone when appropriate to the research objectives of the study. Additional research is needed to better understand barriers to participation in specimen collection, particularly among younger and minority respondents. We are hopeful that future research will help to increase return rates and reduce the areas of bias in future studies incorporating these techniques.

REFERENCES

Caspi, A., McClay, J., Moffitt, T. E., Mill, J., Martin, J., Craig, I. W., et al. (2002). Role of genotype in the cycle of violence in maltreated children. *Science, 297*, 851–854.

Caspi, A., Sugden, K., Moffitt, T. E., Taylor, A., Craig, I. W., Harrington, H. L., et al. (2003). Influence of life stress on depression: Moderation by a polymorphism in the 5-HTT gene. *Science, 301,* 386–389.

Eley, T. C., Sugden, K., Corsico, A., Gregory, A. M., Sham, P., McGuffin, P., et al. (2004). Gene-environment interaction analysis of serotonin system markers with adolescent depression. *Molecular Psychiatry, 9*, 908–915.

Engel, L. S., Rothman, N., Knott, C., Lynch, C. F., Logsden-Sackett, N., Tarone, R. E., et al. (2002). Factors associated with refusal to provide a buccal cell sample in the Agricultural Health Study. *Cancer Epidemiology Biomarkers and Prevention, 11,* 493–496.

Freeman, B., Powell, J., Ball, D., Hill, L., Craig, I., & Plomin, R. (1997). DNA by mail: An inexpensive and noninvasive method for collecting DNA samples from widely dispersed populations. *Behavior Genetics, 27,* 251–257.

Garcia-Closas, M., Egan, K. M., Abruzzo, J., Newcomb, P. A., Titus-Ernstoff, L., Franklin, T., et al. (2001). Collection of genomic DNA from adults in epidemiological studies by buccal cytobrush and mouthwash. *Cancer Epidemiology Biomarkers and Prevention, 10,* 687–696.

Harty, L. C., Garcia-Closas, M., Rothman, N., Reid, Y. A., Tucker, M. A., & Hartge, P. (2000). Collection of buccal cell DNA using treated cards. *Cancer Epidemiology Biomarkers and Prevention, 9,* 501–506.

Longnecker, M. P., Taylor, P. R., Levander, O. A., Howe, M., Veillon, C., McAdam, P. A., et al. (1991). Selenium in diet, blood, and toenails in relation to human health in a seleniferous area. *American Journal of Clinical Nutrition, 53,* 1288–1294.

Kozlowski, L. T., Vogler, G. P., Vandenbergh, D. J., Strasser, A. A., O'Connor, R. J., & Yost, B. A. (2002). Using a telephone survey to acquire genetic and behavioral data related to cigarette smoking in "made anonymous" and "registry" samples. *American Journal of Epidemiology, 156,* 68–77.

Saftlas, A. F., Waldschmidt, M., Logsden-Sackett, N., Triche, E., & Field, E. (2004). Optimizing buccal cell DNA yields in mothers and infants for human leukocyte antigen genotyping. *American Journal of Epidemiology, 160,* 77–84.

FEATURE PAPER: Factors Associated with Blood and Tissue Consent in a Population-Based Study of Newly Diagnosed Breast Cancer Patients[Note 1]

Jennifer Parsons, Ron Hazen, and Richard Warnecke, *University of Illinois at Chicago*

INTRODUCTION

As studies of health disparities have begun to incorporate genetic and environmental influences along with social ones, survey researchers are increasingly posed with the challenge of collecting various biological specimens in addition to the interview. Collecting some samples is complicated by the fact that they involve invasive procedures (e.g., blood draws) and the results of these tests are not usually shared with the respondent. Privacy issues and other concerns about genetic research may lead to reluctance by study participants to give consent for studies of their DNA.

Moreover, there is some evidence to suggest that minorities are less likely to contribute biological specimens during population surveys. Most of these studies have focused specifically on collection of samples for DNA analysis. In the National Birth Defects Prevention Study (NBDPS), buccal cell collections were significantly lower among minority groups, particularly non-Hispanic Blacks and Hispanics (Crider, Reefhuis, Woomert, & Honein, 2006). Similarly, data from the 1999 and 2000 NHANES show that consent for blood samples to be included in a national repository for genetic research was lowest among women and African-American participants (McQuillan, Porter, Agelli, & Kington, 2003). There are similar findings in research on clinical trial participation. Many studies show that racial and ethnic minorities are significantly less likely to participate in cancer clinical trials than Whites (Murthy, Krumholz, & Gross, 2004; Moorman et al., 2004). While consent for biospecimen collection is generally high, further exploration of race and gender differences is suggested by these and other studies. In this paper, we report preliminary findings from a population-based study of newly diagnosed breast cancer patients in Chicago that included a request for a blood sample, as well as for samples of existing breast tissue that would be stored for future research.

METHODS

Study Overview

The University of Illinois at Chicago is one of eight sites funded by several divisions within the National Institutes of Health to study racial disparities in health. The UIC Center for Population

Health and Health Disparities (CPHHD) receives support from the National Cancer Institute and has been in operation since the fall of 2003. Breast Cancer Care in Chicago (BCCC) is the major project of this center; it is focused on exploring the reasons for disparities in stage of breast cancer at diagnosis among White, African-American, and Latina women. It is well documented that the likelihood of developing breast cancer is higher for White women than for African-American and Hispanic women, yet African-American women are twice as likely as White women to die within five years of a breast cancer diagnosis and Hispanic women are 1.5 times as likely (Jacobellis & Cutter, 2002; Eley et al., 1994). When the BCCC study is completed in 2008, approximately 925 diagnosed breast cancer patients in Chicago will have been interviewed.

Study Components

Subjects who agree to enroll in the BCCC study are required to complete an in-person interview about their experiences on the path to diagnosis and treatment of breast cancer; the kinds of support received from family and friends; access to health care; personal health beliefs; and stress. A $50 cash incentive is paid for completing this interview. In addition, consent is sought for five optional study components:

1. Assistance in obtaining interviews with the patient's friends and family members, who are enumerated during the interview, which carries an additional $25 incentive[Note 2];
2. Permission for access to the medical record for abstraction of data related to breast cancer screenings and diagnosis;
3. Permission to obtain a copy of the pathology report relating to the diagnosis of breast cancer;
4. Permission to obtain a sample of the tissue used for diagnosing the patient's cancer to perform a standardized assessment of markers that are well-established predictors of breast cancer prognosis as well as store the sample for future research; and
5. A blood sample to measure cytokine and other markers of stress/immune function for which there is an additional $50 incentive.

Study Population

Eligible patients are recruited from 67 hospitals in Chicago and adjacent suburbs that diagnose and treat breast cancer patients. Cases are identified by the Illinois Department of Public Health (IDPH) through a rapid case ascertainment process. To be eligible, cases must have a histologically confirmed diagnosis of either *in situ* or invasive first primary breast cancer (Stage 0–IV) and be (1) female; (2) a resident of Chicago at the time of diagnosis; (3) African American, Caucasian, or Hispanic; (4) diagnosed between the ages of 21–79; (5) and have been diagnosed within the previous three months.

Subject Recruitment

No sooner than 45 days from their date of diagnosis, IDPH sends each new patient a letter signed by the Director and a study brochure that detail, in full, all of the elements of the study. These materials explain the purpose of the study and ask the patient to contact IDPH or the UIC Survey Research Laboratory (SRL) directly for further information and to make an appointment for an interview. A respondent also may enroll in (or refuse) the study via a tear-off coupon attached to the brochure. If neither IDPH nor SRL has heard from the patient within 10 days of the initial mailing, a follow-up letter is sent by IDPH. If there is still no response after another 10 days, the IDPH recruiter calls the patient to determine if the materials were received. If the patient is interested in participating, she is connected to SRL, where all screening and recruitment occurs. In this process, the role of IDPH is to inform the eligible subjects of the study and their opportunity to participate; they are not responsible for recruiting or screening the patients.

At the time of the screening, the potential subject is told about the optional components of the study. The patient also is told that she does not need to commit at the time of the phone call. The goal of the recruitment effort is merely to ensure that the patient is informed of all study elements.

The decision to fully disclose all of the elements of the study in advance was carefully considered. The process is significant to understanding the outcomes reported in this paper. The BCCC project was developed in partnership with Healthcare Consortium of Illinois, a community-based organization that addresses health disparities in five underserved community areas in Chicago. Input from these partners informed our full-disclosure protocol. Moreover, the advantages of full disclosure were suggested by results from one of the study co-investigator's previous studies, which was a population-based case control study of kidney cancer that involved an interview and optional biospecimens. In that study, a split-ballot experiment was implemented with two forms of the initial contact letter: one group was fully informed about the request for biospecimens and the other was not. The results showed significantly higher consent to biospecimens—particularly blood—among the informed group (Colt et al., 2005). Based on this input, the brochure, letter, and screening clearly defined all aspects of the study.

RESULTS

The results reported here are based on 469 completed interviews (243 African American, 70 Hispanic, 156 White); the

Table 1. Logistic Regression Model: Blood Consent (Reference = White)

Variable	Odds Ratio	Lower CI
African American	.70	(.40, 1.22)
Hispanic	.47	(.22, 1.00)
Stage*	.70	(.54, .91)

Income	.83	(.65, 1.06)
Age*	.97	(.95, .99)
Education	.76	(.56, 1.02)

*p < .05, Nagelkerke R^2 = .068.

greater number of African-American interviews in the analysis is not indicative of differential participation rates but the rate at which the larger Chicago hospitals with predominantly White patient populations came on board and started ascertaining patients. As shown in Figure 1, the vast majority of enrolled patients consented to the optional study components: 90% to medical records, 91% to pathology reports, 86% to tissue samples, and 76% to blood. We looked for variation in consents to these study elements by various sociodemographic variables but found no variation (see Figures 2–6), with the exception of stage at diagnosis: the more advanced cancer stage, the less likely blood consent was obtained. This is not surprising in light of the fact that many patients are already undergoing treatment by the time our interview takes place. We entered these variables into a logistic regression model for blood consent, and those results are presented in Table 1. The bivariate association of consent with stage at diagnosis was significant, as was age. Older respondents were less likely to consent to give a blood sample.

DISCUSSION

To date, the BCCC response rate is approximately 51%; the refusal rate is 43%. Two factors may be largely responsible for these rates. First, this is the first rapid case ascertainment study conducted by the Illinois Department of Public Health. Most states, including Illinois, have cancer registries and typically mandate cancer reporting without patients' consent. So it is likely that few subjects who received information about the BCCC study from IDPH knew that cancer is a reportable disease and a cancer registry exists. In the modern-day HIPAA environment, in which patients are sensitized to HIPAA rights at every physician and laboratory visit, HIPPA is a significant concern that cannot be overlooked

Figure 1. Overall Consents (n = 469)

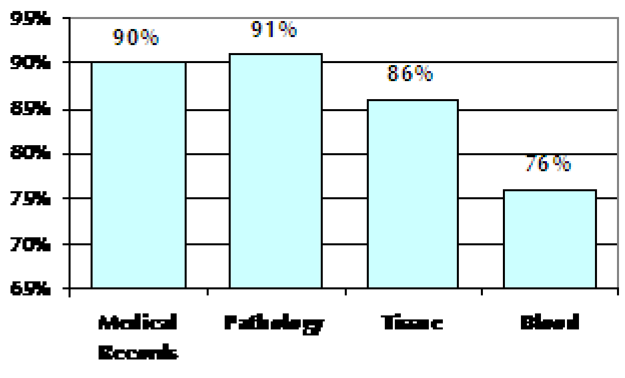
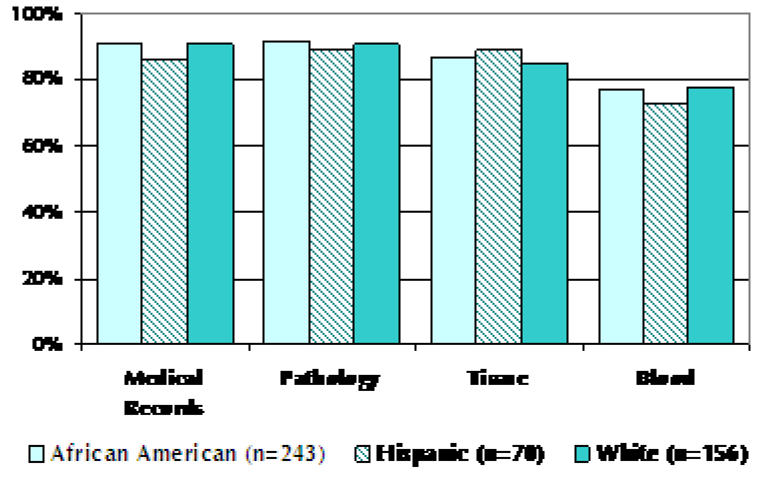


Figure 2. Consents, by Race (n = 469)



when trying to understand consent and cooperation rates. Secondly, IDPH waits 45 days before mailing the initial study materials to eligible patients. Due to the detailed information we are collecting on their path to diagnosis, however, it is critical to the study design that the patients be interviewed as close to their diagnosis date as possible. But most breast cancer patients are already in treatment at the time they are informed about the study; those with more advanced stages of disease may in fact be too ill to participate. Finally, once a subject declines participation, we are not allowed to recontact them.

Overall, our consent rates to the optional study elements, particularly the biospecimens, are respectably high, and we did not find any variation by race. Moreover, refusals to enroll in BCCC are similar by race. Our preliminary results suggest that once subjects decide to participate in the study, they are comfortable consenting to all components, particularly since they knew what those components were at the time they enrolled. It is possible that those who refuse to enroll in the study are actually refusing to these elements, a pattern found in another study enrolling colorectal cancer patients in a genetics study (Ford et al., 2006; Evans, Stoffel, Balmana, Regan, &

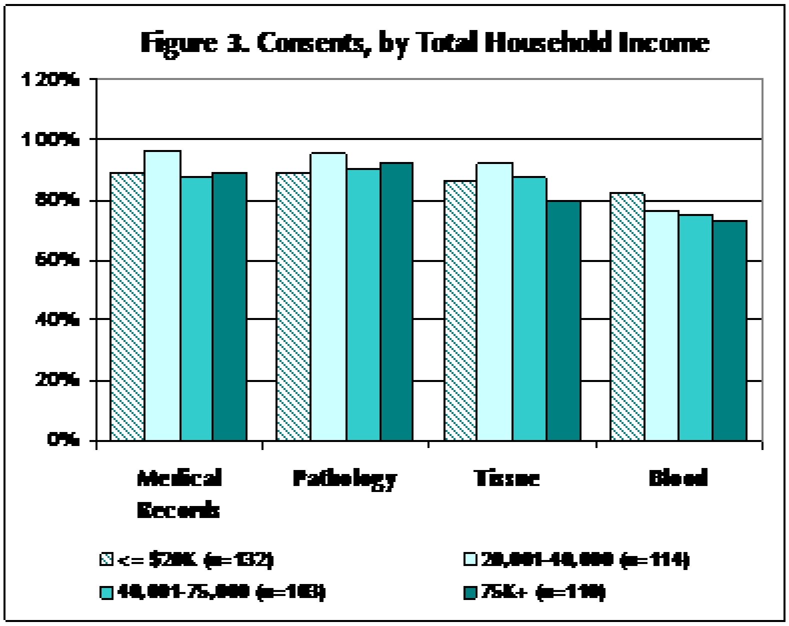


Figure 3. Consents, by Total Household Income

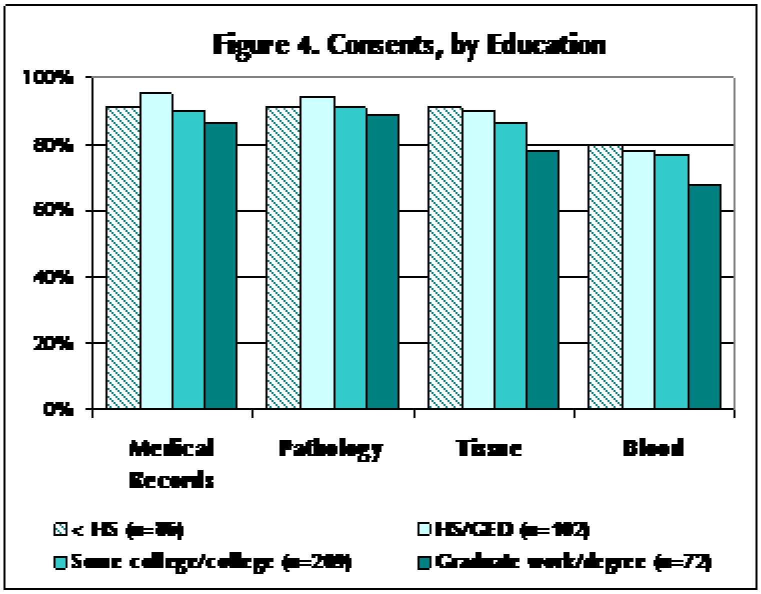


Figure 4. Consents, by Education

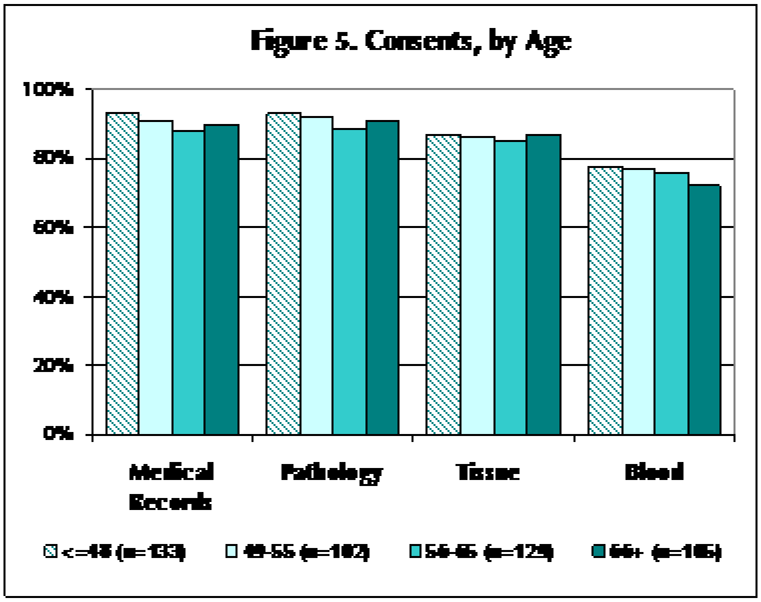
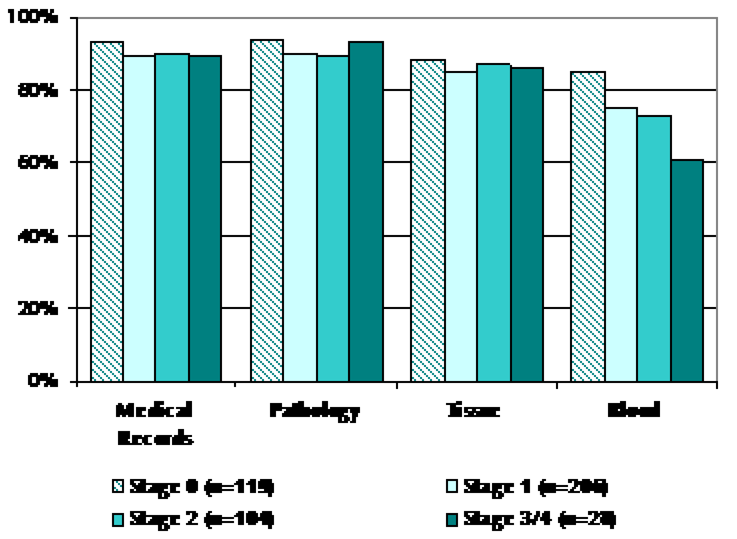


Figure 5. Consents, by Age

Syngal, 2006). However, our results are preliminary and represent only about half of the total number of completes expected in this study. Fortunately, we will have an opportunity to conduct a rigorous nonresponse analysis upon receipt of a de-identified data file from IDPH that lists key demographics and stage of diagnosis for all women contacted for the study. We therefore will be able to control for the selection bias in the analyses presented here.

Figure 6. Consents, by Stage at Diagnosis



REFERENCES

Colt, J. S., Wacholder, S., Schwartz, K., Davis, F., Graubard, B., & Chow, W. (2005). Response rates in a case-control study: Effect of disclosure of biologic sample collection in the initial contact letter. *Annals of Epidemiology, 15*, 700–704.

Eley, J. W., Hill, H. A., Chen, V. W., Austin, D. F., Wesley, M. N., Muss, H. B., et al. (1994). Racial differences in survival from breast cancer. Results of the National Cancer Institute Black/ White Cancer Survival Study. *JAMA, 272,* 947–954.

Ford, B. M., Evans, J. S., Stoffel, E., Balmana, J., Regan, M. M., & Syngal, S. (2006). Factors associated with enrollment in cancer genetics research. *Cancer Epidemiology Biomarkers & Prevention, 15,* 1355–1359.

Jacobellis, J., & Cutter, G. (2002). Mammography screening and differences in stage of disease by race/ethnicity. *American Journal of Public Health, 92,* 1144–1150.

Moorman, P. G., Skinner, C. S., Evans, J. P., Newman, B., Sorenson, J. R., Calingaert, B., et al. (2004). Racial differences in enrollment in a cancer genetics registry. *Cancer Epidemiology Biomarkers & Prevention, 13,* 1349–1354.

Murthy, V. H., Krumholz, H. M., & Gross, C. P. (2004). Participation in cancer clinical trials: Race-, sex-, and age-based disparities. *JAMA, 291,* 2720–2726.

[Note 1] Funded by grant #P50CA106743 from the National Cancer Institute.

[Note 2] In February 2007, we amended this protocol to pay $100 for the interview. We continue to ask for the subjects' help in recruiting their alters, but that consent no longer pays an additional incentive.

FEATURE PAPER: Challenges in Collecting Survey-Based Biomarker and Genetic Data: The NHANES Experience

Clifford Johnson, David Lacher, Brenda Lewis, and Geraldine McQuillan,
National Center for Health Statistics

The use of direct physical measures is critical and necessary in order to estimate the extent of various diseases and risk factors for disease in the population. The use of such measures in clinical settings and interventions has occurred for many years. In recent years, there has been an increasing interest in collecting biological data in population-based surveys.

Biomarker data and other physical measures have been collected in the National Health and Nutrition Examination Survey (NHANES) since its beginning in 1960 (CDC/NCHS, n.d.). During these more than 45 years, numerous challenges have been encountered relative to the collection and laboratory processing of biomarker data. In recent years, the collection and processing of genetic specimens has been part of NHANES, and many lessons have been learned about the collection of this type of information in a general population-based survey. The focus of this paper is to enumerate many of these challenges and describe the changes made to address these data collection and processing issues in NHANES.

Table 1. Laboratory Tests in NHES I, NHES II, & NHES III

TEST	I	II	III
I. Hematological Assessments			
a. Hematocrit			x
b. Red blood cell antigens			x
II. Serum Biochemical Assessments			
a. Cholesterol, total	x		x
b. Glucose	x		
c. Protein bound iodine			x
d. Plasma proteins			x
III. Syphilis Screening			x
IV. Bacteriuria			x
V. Urine Assessments			
a. Urine sugar	x		
b. Urine albumin	x		

The origin of the NHANES is the National Health Survey Act of 1956, which formulated the need for national population surveys to assess the extent of illness and disability in the U. S. population. The National Health Interview Survey (NHIS) was the first survey created to respond to this public health need and was first fielded in July 1957. For 50 years, this survey has been in continuous operation collecting data on health and illness of the population using standardized in-person household interviews.

The need for additional data on health status that could best (or only) be assessed using direct physical measures also was recognized, and in 1958, planning for the first National Health Examination Survey began. An early decision was to collect these measures in a standardized environment; this led to the construction of mobile examination centers to collect this information. These centers could be moved from one location to another so that all data collected in the survey would utilize standard procedures and equipment. A limited set of biological specimens were included in the first NHES survey (NHES I) and in the subsequent survey on adolescents (NHES III) (Table 1). There were no biological tests done on children who participated in the NHES II survey (Table 1).

In 1971, a nutrition component was added to the NHES, and the survey became known as the National Health and Nutrition Examination Survey (NHANES). The number of biomarkers collected in NHANES I (1971–1975) was much greater than the number collected in any of the three NHES surveys in the 1960s. In addition, the survey covered a much wider age range (1–74 years) than any of the previously conducted NHES surveys. Tests were completed on whole blood, serum, and urine samples. Some of the new biomarkers were added to address specific nutrition issues, but others were added to provide national reference data for selected immunization and infectious disease assessments (Table 2).

The expansion of the number of biomarkers collected in NHANES I was accompanied by an increase in the number of data collection and methodological issues associated with these laboratory assessments. There were limited quality assurance procedures in the field during specimen collection and in the laboratories during testing. There were also delays in coding and processing the results. These factors made it impossible to release various test results because issues of data quality and interpretation could not be addressed in a timely manner. In addition, the expansion of the survey to include young children proved to be problematic because of a high number of refusals for the venipuncture or unsuccessful blood draws even with acceptance of the venipuncture. An early lesson learned was the need to have phlebotomists that were skilled in drawing blood on children. Making this a requirement for the position resulted in a drop in missing data from 70% to about 30%.

Table 2. Laboratory Tests in NHANES I, NHANES II, HHANES, & NHANES III

TEST	I	II	H	III
I. Hematological Assessments				
a. Sedimentation rate	x			
b. Differential smears	x	x	x	x
c. Hematocrit	x	x	x	x
d. Hemoglobin	x	x	x	x
e. Cell counts	x	x	x	x
f. Neutrophil hypersegmentation				x
g. Mean cell volume	x	x	x	x
h. Red cell distribution width				x
II. Serum Biochemical Assessments				
a. Folic acid	x	x	x	x
b. Iron & total iron-binding capacity	x	x	x	x
c. Vitamin C		x		x
d. Vitamin D (25-hydroxy D)				x
e. Zinc & copper		x		
f. Vitamin A	x	x	x	x
g. Vitamin B-12	x			
h. Plasma glucose (GTT)		x	x	x
i. Selenium				x
j. Cholesterol, total	x	x	x	x
k. HDL & LDL cholesterol		x	x	x
l. Triglycerides		x	x	x
m. Apolipoproteins AI & B				x
n. Total & ionized calcium				x
o. Ferritin		x	x	x
p. Biochemistry profile:				
1. Total carbon dioxide			x	x
2. Blood urea nitrogen	x		x	x
3. Total bilirubin	x		x	x
4. Alkaline phosphatase	x	x	x	x
5. Cholesterol	x	x	x	x
6. SCOT, AST	x	x	x	x
7. SGPT, ALT			x	x
8. LDH			x	x
9. Total protein	x		x	x
10. Albumin	x	x	x	x
11. Creatinine	x	x	x	x
12. Glucose			x	x
13. Calcium	x		x	x
14. Chloride			x	x
15. Uric acid	x		x	x
16. Phosphorus	x		x	x
17. Sodium	x		x	x
18. Potassium	x		x	x
q. Carotene profile				x
r. Cotinine				x
s. Bile salts		x		
t. Pesticides		x	x	
u. Syphilis serology	x	x	x	
v. Hepatitis A & B serology		x	x	x
w. Tetanus	x		x	x
x. Diphtheria, rubella, polio	x			
y. Herpes simplex I & II		x		x
z. IgE				x
aa. Human immunodeficiency virus				x

bb. C-reactive protein				x
cc. Rheumatoid factor				x
dd. Follicle stimulating hormone				x
ee. Luteinizing hormone				x
ff. Thyroxine (T4)				x
gg. Thyroid stimulating hormone (TSH)	x			x
hh. Antithyroglobulin antibodies				x
ii. Antimicrosomal antibodies				x
jj. Insulin				x
kk. C-peptide				x
ll. Plasma fibrinogen				
III. Whole Blood Biochemistry Assessments				
a. Protoporphyrin		x	x	x
b. Lead		x	x	x
c. Folate		x	x	x
d. Carboxyhemoglobin		x	x	
e. Glycosylated hemoglobin			x	x
f. Priority toxicant volatiles				x
IV. Urinary Assessments				
a. Urinalysis	x	x	x	
b. Pesticides		x	x	
c. Riboflavin	x			
d. Thiamin	x			
e. Cadmium				x
f. Creatinine	x	x		x
g. Microalbumin				x
h. Urinary iodine				x
i. Pregnancy test	x			x
j. Priority toxicant phenols				x
V. Excess and Reserve Vials				
a. Serum	x	x	x	x
b. White blood cells for DNA banking				x

Other challenges and problems occurred in the laboratory in the NHANES mobile examination center in NHANES I. Numerous vials were lined up next to each other in racks after aliquots of serum had been processed. The vial to be used for serum folate testing was placed next to the vial for vitamin C testing. The preparation of the serum folate vial (according to the protocol) required the addition of a "pinch of ascorbic acid" to the tube. Lab technicians did not put a stopper in the vitamin C vial before adding the pinch of ascorbic acid to the folate vial. The result was numerous abnormally high vitamin C levels that were not physiologically possible in the population. Thus, the entire set of data for vitamin C was deemed unusable and never released.

NHANES II (1976–1980) brought increased numbers of biomarkers and the first environmental assessments (blood lead and selected pesticides) (Table 2). As in NHANES I, methodological issues related to data collection protocols and laboratory methodologies were encountered. For example, vials that were thought to be free of environmental contaminants turned out not to be, and various environmental assessments collected in the course of NHANES II were declared methodologically unsound and never released. These protocol and equipment problems were corrected prior to the fielding of NHANES III.

During the course of data collection in NHANES II, a practical and fiscal decision was made to change the laboratory method for serum folate and red blood cell folate from a microbiological method to a more automated radioimmunoassay method. However, the two folate lab methods did not produce comparable results at all levels of values. Thus, upon review of the raw data (after the survey was completed), an expert panel determined that the data from the two folate lab methods could not be combined. Thus, the ability to calculate national reference data for serum and red cell folate was not possible (Life Sciences Research Office, 1984). This example (and a few others) led to crossover studies being conducted with method changes (whenever possible) in all NHANES surveys since that time. These crossover studies are an important component of blood and urine specimen testing protocols and are critical for analyses that are conducted to address time trends.

The number of blood and urine biomarkers included in NHANES III (1988–1994) increased significantly from the number of biomarkers in NHANES II (Table 2). This occurred for two reasons. First, many new laboratory methods had been developed that used less volume of serum or plasma; thus, more assessments could be included in the survey without increasing the volume of blood collected from each person selected for the survey. The second reason for the increase in the number of lab assessments was the availability of a variety of new lab methods. So, as the overall content and complexity of NHANES grew, so did the use of blood and urine specimens to address a wide array of public health issues.

This expansion in the number of laboratory biomarkers significantly increased the complexity of survey operations and specimen collection. The number of vials of serum increased, requiring increased staff to process the specimens in the field. The need to ship over 100,000 vials of blood per year to numerous labs around the country using dry ice added further logistical challenges. Collecting and shipping large numbers of lab specimens is a significant impediment to the inclusion of biomarkers in population-based surveys.

Another significant change in the number of laboratory assessments occurred with the implementation of the ongoing and continuous NHANES beginning in 1999. The development of numerous environmental lab assays increased the total number of lab biomarkers by tenfold, with little increase in the volume of blood and more utilization of urine than in previous surveys.

In addition, DNA specimens were added back into the survey with additional consent language that separated consent for the general survey and lab biomarkers from the stored biologic specimens that include serum, plasma, urine and DNA specimens. Survey participants could agree to (or refuse) all of the lab biomarkers, agree to or refuse the planned use of stored biologic specimens, and agree to or refuse the collection and use of the DNA specimens. This has resulted in a much more complicated administrative responsibility for NHANES staff with respect to use of lab biomarkers.

In addition to administering the continuous survey, the NHANES staff administers an investigator-driven research program where researchers can submit proposals for the stored samples on an ongoing basis. These proposals must undergo both technical and ethics review before specimens that have been stored from consenting participants can be used for these research projects. The availability of these specimens, though, has greatly increased the research potential of the survey with the addition of over 20 additional laboratory data sets in the past ten years.

More recently, a separate process was developed for the use of the NHANES III DNA specimens; it currently is being adapted for use with the NHANES 1999–2002 DNA specimens. The collection of DNA specimens in NHANES has had many challenging issues. Although informed consent was acquired from each survey participant during the 1991–1994 time period for which the specimens were collected, by the time the survey was completed and the samples prepared for analysis, the Ethics Review Board ruled that the original informed consent was not adequate for genetic research and that the specimens could only be used in an anonymous fashion and not linked to most of the other NHANES III data. The restriction of anonymization greatly reduced the usefulness of the NHANES phenotypic data; thus, for a number of years, the NHANES III DNA was not utilized. After the publication of the *Report and Recommendations of the National Bioethics Advisory Commission* in August 1999 on research involving human biologic materials (National Bioethics Advisory Committee, 1999), the NHANES program obtained Ethics Review Board approval to link the genetic data with other survey data in a controlled and restricted data access environment (the NCHS Research Data Center). A similar approach is being utilized for the NHANES 1999–2002 DNA samples collected in this subsequent time period.

Throughout the 46 years of collection of laboratory biomarkers in NHANES, a number of other general issues have arisen. Some of these are summarized below.

One of the most significant of these issues is the problem that occurs when an existing laboratory method is discontinued and a new method is substituted for a particular assay. How and when to conduct crossover studies (to compare the two methods) is an important decision (and critical to the use and interpretation of the data). For NHANES, there are instances where these types of studies did not occur, and we were unable to determine whether changes over time were real, methodological, or both. Even if a crossover study is conducted, there may be inadequate sample sizes for the study; this can lead to difficulties knowing the relationship of the two methods at the "tails of the distribution." On many occasions, that is the area of greatest public health significance, and the lack of an adequate crossover study can result in uncertain interpretation of results.

In our NHANES experience, we learned that the use of blind quality control specimens is critical. Even though most labs have internal quality control procedures in place, there is the chance that the lab is "not in control," and the only way to monitor that possibility is by sending blinded split-sample specimens to the lab. The lab and lab technicians do not know which of the specimens are of this type. They are aware of their own internal quality assurance control specimens, and that knowledge can influence their handling and processing procedures. Over time, the NHANES program has found quite a few instances where these blind quality control specimens were the only way that problems in laboratory procedures were discovered and corrected.

Another issue is the ethical responsibility to report results to sample persons who participate in the survey. This requires timely analysis and reporting of results from labs to NCHS and then timely reporting of these results to participants by NHANES program staff. In addition, there needs to be some agreed-upon clinical cutpoints that can be utilized in the reporting of the results. If there are no agreed-upon clinical criteria for abnormal values, then results are not reported to individual participants. There is an ongoing responsibility to review new information to determine whether a lab result that was not reportable in the past is now reportable.

This reporting of findings in a timely manner influences what lab tests may be done on stored specimens at a later point in time. The NHANES program along with the survey's Ethics Review Board has decided that any reportable lab biomarker will not be done on stored specimens because the subject could have been examined many years earlier, and later reporting of a clinically significant biomarker is problematic. The assessment of what research laboratory tests may be clinically significant biomarkers has been a challenge. Thus, to date, most research on NHANES stored specimens has been for new and emerging biomarkers that do not have established clinical cutpoints. In spite of this limitation, many stored specimen biomarker proposals have been approved for previous NHANES surveys, and the results have been released on public use data files.

The recent development of biomarker tests that can utilize blood from a finger stick or from a saliva sample will make the inclusion of these assessments more feasible for household-based population surveys. The challenge faced with this approach is whether the laboratory methods that utilize these samples produce comparable results to the traditional blood sample. In many cases, the answer to this question is not known yet. If these less invasive tests prove comparable and reliable, the potential for collecting biomarkers in other surveys increases dramatically. Even so, there remain many logistical complications for any household-based survey attempting to collect biomarkers and genetic data. Training interviewers to be phlebotomists is much more difficult than training phlebotomists to be interviewers. In some cases, it may require an interviewer and phlebotomist team to successfully collect both interview and biomarker data in the home. This option would result in significant cost increases for survey operations (let alone the numerous issues related to handling of blood and urine specimens in a household setting). Even if interviewers can be trained to collect blood from a finger stick, standardization of collection procedures and handling of specimens remains a significant operational constraint. In the case of NHANES, the mobile examination center with a lab and lab staff has remained the mode for biomarker data collection for the entire history of the survey.

In summary, the collection of biomarkers and genetic data in population-based surveys is a significant challenge. The issues include how to obtain informed consent, what staff to use to collect and process the biomarkers, how to collect and process the specimens in a timely manner, how to select a laboratory and lab method, and how to implement quality assurance procedures to ensure that the results will be valid and interpretable. Over the 46 years that biomarkers have been collected, processed, and analyzed in NHANES surveys, almost every logistical and methodological complication that can occur *has* occurred. These challenges continue to occur because science moves on, methods change, and people do not always foresee what might occur in a real-time survey operation. The important lesson is to learn from mistakes (and successes) and to use this knowledge in future surveys.

REFERENCES

Centers for Disease Control and Prevention, National Center for Health Statistics. (n.d.). *National Health and Nutrition Examination Survey.* Retrieved August 17, 2007, from www.cdc.gov/nchs/nhanes.htm

Life Sciences Research Office. (1984, October). *Assessment of the folate nutritional status of the U.S. population based on data collected in the second National Health and Nutrition Examination Survey, 1976–1980.* Rockville, MD: Federation of American Societies for Experimental Biology.

National Bioethics Advisory Commission. (1999). *Research involving human biological materials: Ethical issues and policy: Vol. 1. Report and recommendations of the National Bioethics Advisory Commission.* Rockville, MD: Author. Retrieved August 17, 2007, from http://bioethics.georgetown.edu/nbac/hbm.pdf

FEATURE PAPER: Incorporating Biomarkers for the Fourth Wave of the National Longitudinal Study of Adolescent Health

Amy Ladner, *RTI International*

INTRODUCTION

The National Longitudinal Study of Adolescent Health (Add Health) is a study of a nationally representative sample of more than 20,000 individuals who were in grades 7–12 in 1994–1995. Since the initial in-school questionnaires were administered, these sample members have been followed through adolescence and the transition to adulthood with three in-home interviews. This landmark study was designed by a nationwide team of multidisciplinary investigators from the social, behavioral, and health sciences led by researchers at the University of North Carolina and funded by the National Institute of Child Health and Human Development with cofunding from 17 other federal agencies (Harris, 2006). Plans for a fourth in-home interview with respondents who will be 24–32 years old currently are underway, with a pretest of 300 sample members slated to start in April 2007.

Given the size and spread of the Add Health sample and the nonclinical setting of our interviews, we have chosen methods to collect biological data that are noninvasive, innovative, cost-effective, and practical for population-level research. As we plan and move into Add Health Wave IV data collection, we recognize the inherent challenges in collecting numerous biomarkers and other health data in a field setting. This paper will document the extensive preparation, interviewer training, and specimen tracking system development required to ensure the study's success.

OVERVIEW OF ADD HEALTH WAVE IV

Data to be collected at Wave IV from approximately 17,000 participants include

- Social and economic status, behaviors, and experiences
- Psychological status and experiences
- Reported health status and health behaviors
- Environmental contexts (residence, college)
- Spatial location of residence
- Extensive biomarkers, including physical measurements, blood pressure, lipids profile, DNA, and other measures of chronic stress, metabolic syndrome, and immune function (Harris, 2005).

Wave IV will focus on three major health concerns for the Add Health cohort: (1) obesity, (2) health risk behavior, and (3) stress (Flegal, Carrol, Ogden, & Johnson, 2002; McEwen, 1998; Schulenberg, Maggs, & Hurrelmann, 1997). These were selected due to the prevalence of young adults in the population and the widespread consequences for adult health and well-being. With the addition of data and biomarkers collected in Wave IV, we will be able to examine the factors contributing to obesity, investigate the consequences of longer exposures to risky lifestyles on health status, and link sources of chronic stress in the early stages of the life course to subsequent life course trajectories of cumulative physiological risk.

ADD HEALTH WAVE IV BIOMARKER COLLECTION

The choice of biological data for Wave IV is driven by scientific knowledge of the leading causes of health at this and future developmental stages of the Add Health cohort, the role of specific biological processes in causation, and the ability of specific measures to characterize these processes. We plan to collect biological data on anthropometric, cardiovascular, metabolic, immune function, and inflammatory processes that capture important health conditions associated with obesity, chronic stress, and poor health behaviors, as well as critical markers of future health risks, such as diabetes, cardiovascular disease, coronary artery disease, physical and cognitive decline, poor kidney functioning, and early mortality. Within these scientific criteria, the choices of biological measures were constrained by the feasibility, validity, and reliability of methods used to obtain biological specimens in a nonclinical setting. Table 1 lists the domains of biological measures that will be collected during Wave IV.

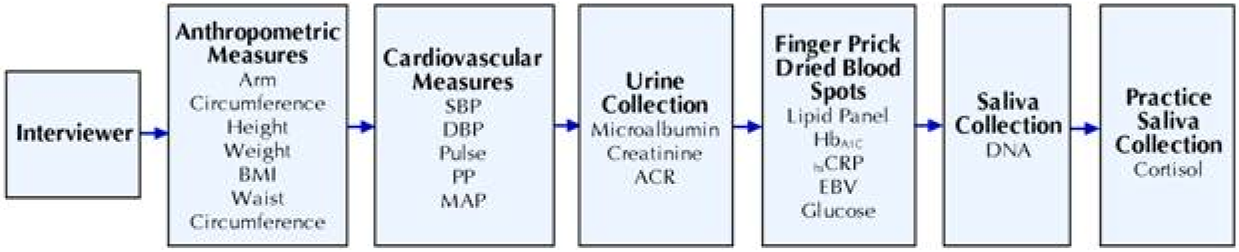
Table 1. Add Health Wave IV Domains of Biological Measures

Domain	Specimen	Measure
Anthropometric		Height, weight, BMI, arm and waist circumference
Cardiovascular		Blood pressure, pulse rate, pulse pressure, mean arterial pressure
Metabolic	Dried blood spots	Lipid panel, glycosylated hemoglobin
Inflammation	Dried blood spots	C-reactive protein
Immune function	Dried blood spots, saliva	Epstein-Barr virus antibodies, cortisol
DNA	Saliva	Candidate gene loci and SNP panels
Kidney function	Urine	Microalbumin, creatinine

Data Collection Sequence & Measures

Data and specimen collection during the interview will follow the sequence presented in Figure 1. Collection protocols and intervening rest periods are designed to maximize efficiency in obtaining informed consent and minimize putative carryover effects. Total time to collect all biological specimens and measurements is 40 minutes. We also will ask respondents to self-collect three saliva samples the day following the interview for cortisol assay.

Figure 1. Biomarker Data Collection Sequence During Interview



Anthropometric Measures

As in earlier waves, trained and certified interviewers will measure the weight and height of Wave IV participants who are dressed, have removed their shoes, and are standing on an uncarpeted floor (where possible). Weight will be measured to the nearest 0.2 lb using the Tanita HD 351 Weight Scale (max: 440 lb). Height will be measured to the nearest 0.25 inch using a carpenter's square, tape measure, and Post-it® note. Arm and waist circumference will be measured to the nearest 0.25 inch using a Seca 200 circumference tape measure (max: 78 in). Arm circumference will be used to guide selection of an appropriately sized blood pressure cuff. Waist circumference will be measured midway between the lowest rib and the superior border of the iliac crest at end-expiration. Body mass index will be calculated from weight and height and interpreted in accordance with *Clinical Guidelines on the Identification, Evaluation, and Treatment of Overweight and Obesity in Adults—The Evidence Report* (NIH, 1998).

Cardiovascular Measures

Trained and certified interviewers will measure the pulse and systolic and diastolic blood pressure of participants and key the results into the computer according to a standardized protocol. Participants will be asked to avoid caffeinated beverages and foods, heavy physical activity, smoking, and alcohol for eight hours prior to the interview. Compliance with these requests will be recorded in the questionnaire along with other factors known to affect blood pressure and/or pulse (medication use, time of day). After a five-minute quiet rest period, seated values of SBP, DBP (mmHg), and pulse (beats/min) will be automatically recorded to the nearest whole unit using an appropriately sized cuff and the Microlife 3MC1-PC_IB digital oscillometric blood pressure monitor. Three serial determinations will be performed from the right arm (when possible) at 30-second intervals. Pulse pressure and mean arterial pressure will be estimated indirectly. The computer will automatically calculate, store, and display the average of the last two determinations for the purpose of classifying, reporting, and guiding follow-up according to current guidelines from the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure (Chobanian et al., 2003). After an interview has been completed, interviewers will connect the blood pressure monitor to the computer via USB interface to download the readings.

Urine Collection

Microalbuminuria (MA) above 20mg/dL may be an early marker of renal disease. To evaluate MA incidence and prevalence in Wave IV respondents, participants will be asked to provide a random first stream sample of 15 cc. Samples will be packed in insulated coolers with frozen gel packs and shipped to the UNC Kidney Center Chapel Hill, NC) for analysis.

Finger-Prick Dried Blood Spots

Trained and certified interviewers will use finger prick to obtain 10 blood spots (750 800 mL) for dry spot assays of lipid panel, $_{hs}$CRP (mg/L), Hb$_{A1c}$ (%), EBV antibodies, and calculated glucose. Compared to venipuncture, finger prick is a relatively convenient, inexpensive, and noninvasive means of collecting whole blood. Prior to collecting blood spots, interviewers will ask participants to warm their hands in very warm water for approximately one minute. Interviewers then will obtain whole blood spots by (1) cleaning each participant's middle or ring finger with isopropyl alcohol; (2) applying a restriction band to the middle of the upper arm; (3) pricking the selected finger with a sterile, disposable microlancet (Microtainer, Franklin Lakes, NJ); (4) wiping away the first formed drop; (5) placing three drops of blood via capillary action onto standardized filter paper (Biosafe Laboratories, Chicago, IL) to obtain dry spot assays for lipid panel, HbA1c (%) and calculated glucose (mg/dL); and (6) placing seven additional drops via capillary action onto standardized filter paper (Whatman #903, Florham Park, NJ) for dry spot assays of $_{hs}$CRP (one spot), EBV antibodies (one spot), and potential future research (five spots). If one finger prick does not produce at least five drops of blood, the interviewer will perform a second finger prick after participant consent. Blood spots will be air dried per manufacturer instructions (Biosafe—15 minutes, Whatman—4 hours) and then placed in plastic bags with desiccant (Humidity Sponge, VWR) for transport to the laboratory performing the assays (lipid panel—Biosafe Laboratories, Chicago; $_{hs}$CRP—UWMC Immunology Lab, Seattle).

Saliva Collection—DNA

In collaboration with the Institute of Behavioral Genetics in Boulder, Colorado, Add Health will collect, extract, quantify, and store DNA samples from all participants in Wave IV. Genotyping will consist of evaluations of Variable Number Tandem Repeat, Short Tandem Repeat, Single Nucleotide Polymorphism (SNP) or haplotype blocks that will be defined by a panel of SNPs. Genomic DNA will be isolated from saliva samples using the Oragene commercial collection kit (DNAgenotek). The DNA is collected from 2 ml of saliva without swabbing the inside of the cheeks.

Saliva Collection—Cortisol

Add Health participants also will be asked to self-collect three saliva samples for cortisol assay the day after the interview (at awakening, 30 minutes later, before bed) using a 2 ml cryotube (Wheaton Science Products, Millville, NJ) and soda straw. Interviewers will instruct participants to place one end of the straw into the cryotube and one end into their mouth to push saliva through the straw into the tube until the saliva reaches the fill line (1 ml) and have them practice collecting a sample during the interview. The interviewer also will instruct the participant to complete a short checklist following each collection. The checklist is a brief questionnaire designed to collect relevant information about protocol adherence and stressors experienced on the day of collection. The interviewer then will give the saliva collection kits, instructions, checklists, and shipping materials with a pre-addressed paid envelope to each participant. Saliva samples will be sent to Salimetrics LLC in State College, PA.

For the pretest, the cryotubes will be given to the participant stored inside a medication bottle with a MEMS6 TrackCap (Aardex, Switzerland)a lid containing a micro-electronic chip that accurately records the date and time of day that the lid is opened to retrieve a cryotube. Opening times will be used as proxies for sample collection times. In addition, participants will be divided into three groups and told either (1) that saliva collection is time-stamped, (2) that saliva collection is time-stamped for randomly selected participants, or (3) nothing about whether saliva is time stamped. Using this design, we will estimate the difference between participant-reported and TrackCap-recorded sample collection times.

OVERCOMING CHALLENGES TO BIOMARKER COLLECTION

Extensive Planning

The choices of biological measures to collect in Wave IV were constrained by the feasibility, validity, and reliability of methods used to obtain biological specimens in a nonclinical setting by nonmedically trained individuals. In order to determine the collection methods and equipment needed to collect biomarkers for Wave IV, we built an extensive planning period into the project schedule (Table 2). This planning period provided the necessary time needed to examine and test various pieces of equipment, investigate federal and state regulations regarding shipping biological specimens and education requirements for personnel collecting blood spots by finger prick, explore newer technologies for collection and analysis of biomarkers, and convene a panel of experts—the Add Health National Biomarker Advisory Committee—for peer review and advisory inputs.

Table 2. Timeline for Wave IV Data Collection

Task	Start Date	Stop Date	Time
Plan and prepare for pretest	May 2006	Mar 2007	11 months
Conduct pretest	Apr 2007	May 2007	2 months
Revise questionnaire and plan for main study	Jun 2007	Dec 2007	7 months
Conduct main study	Jan 2008	Sep 2008	9 months

The planning period provided an invaluable opportunity for us to alter protocols and equipment needs based on cost and feasibility of collecting measures and biomarkers in the home setting and allowed us to add protocols to measure cardiovascular response to a mental stress test and biomarker reliability. Initially, we planned to measure height with a stadiometer (Seca 214 Road Rod), perform wet blood spot lipid panel analysis with a portable cholesterol monitor (CardioChek PA), and collect saliva for cortisol assay using Salivettes (Salimetrics, State College, PA). After examination of the stadiometer, we decided to alter the height protocol and measure height with a carpenter's square and tape measure to ease interviewer burden (the stadiometer weighed six pounds, did not fit into the interviewer rolling backpack, and required in-home assembly) and save costs. We also altered the finger-prick protocol to perform all blood spot assays on dry spots to ease interviewer burden. To perform wet blood analysis on a portable cholesterol monitor would require interviewers to fill one 40 mL capillary tube with blood for lipid panel analysis, one 15 mL capillary tube with blood for glucose analysis, place the collected blood on disposable test strips, wait for the analyzer to run one test strip before inserting the second test strip (lipid panel strip analysis required three minutes to run), and collect seven remaining blood spots onto standardized filter paper. After a literature review and meeting with the Add Health National Biomarker Advisory Committee, we also decided to collect saliva for cortisol assay with 2 ml cryotubes and soda straws.

In addition to making equipment and protocol changes during the planning period, we added a protocol and study to Wave IV. Following the blood pressure protocol in the interview, we administer a backward-digit-span series, asking the respondent to repeat a set of numbers back to the interviewer in the reverse order. For example, if the interviewer listed 2, 4, the respondent would reply 4, 2, with the series progressively increasing in length. After completion of the backward-digit span, the interviewer performs two additional blood pressure readings 30 seconds apart to measure cardiovascular response to a mental stress test. We also added an Intra-individual Variation Study to Wave IV to estimate the reliability and validity of the biomarker data collected in the field. To this end, we will administer a shortened interview within two weeks of the initial interview to 50 participants in the pretest and 50 participants in the main study and collect all biological measures and samples. We will use the intraclass correlation coefficient as a measure of reliability for monitoring both the collection and processing of biomarkers collected in Wave IV and for quality assurance and control purposes.

Standardizing Collection Protocols

To ensure that the biological data collected in Wave IV are unbiased and valid, we incorporated standardization and quality control practices into biomarker collection protocols, interviewer training protocols, and weekly communications with the interviewers and laboratories. Collecting high-quality biological data starts with hiring interviewers with previous experience collecting biological measurements and samples. For the Wave IV pretest, 15 of the 24 interviewers hired to date have previous experience collecting biomarkers and/or biological measures or blood pressure. Before any interviewer may collect data in the field, he or she must attend a week-long training and pass a rigorous certification conducted at the conclusion of the training. During training, interviewers are instructed on collecting each measurement and sample; given a comprehensive training guide that lists step-by-step instructions and pictures for completing each biomarker protocol, and labeling, packing, and shipping the samples to the appropriate laboratories; and given multiple opportunities to practice each protocol in both scheduled training mocks and after-hours study halls. Once interviewers have passed certification and begin collecting data, we maintain weekly communication with them regarding the quality of specimens collected in the field. We will receive daily reports from the laboratories that not only confirm sample receipt but also list any problems with specimen quality (e.g., blood spot did not completely soak through the filter paper, specimen leaked during transit). We will address these problems immediately and retrain interviewers on particular biomarker protocols if needed.

Monitoring Equipment Function

We also built quality control measures into biomarker protocols by monitoring equipment function. On a weekly basis, interviewers will perform and document calibration of the digital scales by first weighing themselves, weighing their laptops, and then weighing themselves holding their laptops. If the combined weight does not match the summed value and differs by more than one pound, interviewers will notify their supervisor and have the scale replaced. We also incorporated monitoring equipment functioning of the blood pressure monitor into the programming of the interview and in post-interview processing. During the interview, if the blood pressure monitor returns an error message or malfunctions (does not settle on a reading after the cuff deflates), the interviewer will enter this information in the computer. If this problem is experienced three times during an interview, a note appears on the computer screen alerting the interview to discontinue use of the monitor and contact his or her supervisor to have the monitor replaced. We also can observe blood pressure monitor function across interviews by examining the number of malfunctions recorded by a particular interviewer for a specific period of time. Based on the type of error message received and the frequency of malfunction, we can assess whether the problem is with the interviewer or the equipment and address it as appropriate.

Tracking Systems

Collecting and shipping biological samples across the country via multiple couriers so that samples arrive within acceptable timeframes and at appropriate temperatures requires an automated tracking system, standardized communication protocols, and active involvement by the interviewers, field supervisors, project staff, and laboratory personnel. Since each sample requires a specific packing scheme, interviewers will not only be trained and certified on packing each specimen but also will have ready access to written packing instructions and photographs of correctly packed samples in their Job Aids booklet. (Written instructions also will be programmed into the questionnaire.) During the interview, interviewers will scan the barcode on each specimens shipping label using a handheld barcode wand attached to the laptop via USB interface. This includes not only the labels for the specimens that the interviewers will be delivering to Federal Express (blood spots, DNA, urine) but also the barcode tracking number of the U.S. Postal Service (USPS) label for the cortisol sample that the participant will mail after self-collection. These tracking numbers, as well as the interview date, will populate the report of specimens that should be arriving at the laboratories. We also developed reports that capture specimens received by the labs and delinquencies (specimens shipped to the lab but yet reported as received).

Once we have the tracking numbers associated with the shipments to the labs, we can use the online tracking mechanisms provided by Federal Express and USPS to verify delivery prior to lab notification of receipt. We developed an interface that pulls shipment tracking data from Federal Express and USPS into our reports without manual entry of tracking numbers by project staff. As part of Wave IV communication protocol, the majority of participating laboratories report specimen receipt within one week of arrival and upload receipt reports to the secure file server. Our tracking system then automatically compares the list of specimen IDs we expect to be received with the Federal Express and USPS tracking mechanisms and reports of receipted specimens by the labs and identifies delinquent specimens. Delinquency is defined by the type of courier service to the laboratory (Table 3). For specimens shipped via Federal Express, a specimen is considered delinquent if we have not received report of receipt four days after collection. For specimens shipped through USPS, specimens will be considered delinquent if we have not received report of receipt seven days after interview. Project staff will follow up all specimens identified as delinquent with the following order: (1) courier, (2) field supervisor/ interviewer, and

(3) lab. We also will make follow-up calls to participants who agreed to provide the cortisol sample but whose samples did not arrive at the lab.

Table 3. Specimen Delinquency by Courier and Sample

Specimen Status by Day	Federal Express (DNA, blood spots for ${}_{hs}$CRP, EBV, urine)	Federal Express (blood spots for lipid panel)	USPS (salivary cortisol)
Interview	Samples collected, shipped	Sample collected, shipped	Interview
2	Specimen arrives at lab	Specimen arrives at lab	Samples collected
3	Receipt reported	Sample processing	Shipped
4		Results and receipt reported	In transit
5			Sample arrives at lab
6			Receipt reported

CONCLUSION

As we move into the pretest for Add Health Wave IV, we understand the challenges in collecting numerous biomarkers and health measures in a nonclinic setting by nonmedically trained interviewers. While researchers at the University of North Carolina have been planning this data collection effort since the conclusion of Wave III in 2002, under this contract we have spent a year investigating equipment and collection methodologies that are noninvasive, cost-effective, and feasible for population-level research; developing biomarker collection protocols that will result in high-quality, reliable data; and building an automated specimen tracking system that will allow us to manage 85,000 shipments from almost 300 interviewers to multiple laboratories across the U.S. Interviewer training and certification on each health measurement and biomarker collection protocol is essential to the study's success in incorporating standardized, unbiased biological data with preexisting longitudinal Add Health data. At the conclusion of Add Health Wave IV, we will be able to provide unique opportunities to study linkages in social, behavioral, environmental, and biologic processes that lead to health and achievement outcomes in young adulthood.

REFERENCES

Chobanian, A. V., Bakris, G. L., Black, H. R., Cushman, W. C., Green, L. A., Izzo, J. L., Jr., et al. (2003). National High Blood Pressure Education Program Coordinating Committee. The seventh report of the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure (JNC7). *Hypertension, 42*, 1206–1252.

Flegal, K. M., Carrol, M. D., Ogden, C. L., & Johnson, C. L. (2002). Prevalence and trends in obesity among U.S. adults. *JAMA, 288,* 1723–1727.

Harris, K. M. (2005). *The National Longitudinal Study of Adolescent Health (Add Health) Wave IV: Social, behavioral and biological linkages. Overview of program project for Add Health Wave IV*. Chapel Hill, NC: Carolina Population Center.

Harris, K. M. (2006, August). *Add Health Wave IV. Social, behavioral, and biological linkages*. Presented at the Add Health Biomarker Advisory Committee Meeting, Chapel Hill, NC.

McEwen, B. S. (1998). Stress, adaptation and disease: Allostasis and allostatic load. *Annals of the New York Academy> of Sciences, 840*, 33–44.

NIH (National Institutes of Health). (1998). Clinical guidelines on the identification, evaluation, and treatment of overweight and obesity in adultsthe evidence report. *Obesity Research, 6*(Suppl. 2), 51S–209S.

Schulenberg, J., Maggs, J. L., & Hurrelmann, K. (1997). Negotiating developmental transitions during adolescence and young adulthood: Health risks and opportunities. In J. Schulenberg, J. L. Maggs, & K. Hurrelmann (Eds.), *Health risks and developmental transitions during adolescence* (pp. 1–19). Cambridge, UK: Cambridge University Press.

FEATURE PAPER: Ethical, Legal, and Social Concerns When Collecting Biospecimen Data Linked to Individual Identifiers

Barbara Koenig, *Mayo College of Medicine*

Paper not submitted.

SESSION 3 SUMMARY

Alisha D. Baines, *VA Medical Center of Minneapolis*
Michael Davern, *University of Minnesota*

The floor discussion following the Session 3 presentations focused on three major areas: preparation and collection of biomeasures in practice, data quality issues associated with the addition of biomeasure collection, and issues surrounding consent.

PREPARATION & COLLECTION OF BIOMEASURES IN PRACTICE

Preparing for biomeasure collection requires consideration of the amount of materials field interviewers will need to carry. While the study described by Smith and colleagues did not involve the transport of chairs, a Chronic Obstructive Pulmonary Disease (COPD) study had two interviewers conduct each interview because of the need to bring along a host of required equipment, such as a folding table and chair, to the respondent's home for measurement. Smith indicated that a great deal of thought went in to what materials to use and how to best transport them to respondent households. For more basic measures, such as height, it was more efficient to use a tape measure than more standard medical equipment for measuring height. For measures that involved specimen collection, there was consideration of how to move clinical measures into the home. The goal was to get as close to the gold standard as possible but still take into account the portability and robustness of the materials. The equipment was tested ahead of time and was researched to see if it had been tested before and whether it was FDA approved, and the manufacturer's reliability data was reviewed. Further, a pilot period was useful for testing equipment and collection procedures.

DATA QUALITY ISSUES ASSOCIATED WITH THE ADDITION OF BIOMEASURE COLLECTION

The addition of biomeasure collection to the survey research process brings about a concomitant increase in the potential for error. Along with the usual sources of survey error, there also is error associated with the collection and shipment of biological specimens and laboratory error. Such errors can be the result of incorrect recording of data by the interviewer or incorrect collection of the sample by the respondent. There is also the likelihood for additional nonresponse error to be introduced. For the Florida Hurricanes Gene and Environment Study described by Boyle et al., the response rate was only 35% (AAPOR Response Rate 3), and of those who participated, only 41% provided biosamples. For this study—given its short nature (one-month collection period)—this was not a major issue, but in general, it could be a cause for serious concern.

In addition to normal interviewer effects, studies such as those described in the session have the additional issues of increased concern about interviewers' ability to gain cooperation and their skill at collecting the biomeasures, especially if they are not medical professionals. Preliminary analyses suggested differential rates of cooperation, but the quality of the data gathered from those who *did* cooperate is not different. There was also a discussion of the differential rates between older Whites and older Hispanics and Blacks in the hurricane study; one explanation for these differences involves mail delivery: the collection kits may not have fit into mailboxes and may have looked enticing to passers-by.

In relation to data issues, the addition of biomarker measurement to survey research introduces an additional data quality paradigm: survey researchers have specific models they use, including error models, while the lab community has tests with known sensitivity and specificity. Thus, while the lab community is not surprised by the variability in their data, the survey community is just becoming aware of it. Further, survey researchers must be aware of the potential and possible sources of measurement error in the laboratory environment as well as the potential for error related to technician effects. As Johnson and colleagues described, NHANES used blind quality checks and discovered problems in laboratory procedures that were not caught by the labs' quality assurance methods.

ISSUES AROUND CONSENT

Discussion surrounding consent first addressed how much information about the biomeasure collection should be provided to potential respondents in advance. While Smith et al. found that cooperation rates were lower when they gave extensive information in a cover letter, Parsons and colleagues provided comprehensive information to potential respondents and observed no evidence that this negatively affected cooperation.

The second consent-related issue centered around the ability of respondents to refuse specific tests to which their biosamples might be subjected. In general, a list of all the tests that could be performed on the biosamples should be provided in advance, and tests in addition to those listed should not be conducted without gaining respondent consent. Consent forms for the studies described in this session were more complex than those used in more standard survey research. While most tests fall under an umbrella consent, some require separate consent. For NHANES, the consent form has multiple places for consent, and participants can refuse certain elements. Further, subjects must be able to indicate if they want test results reported to them. In general, consent forms for studies discussed were multistep and allowed for partial consent. With the ongoing development of new genetic testing procedures, consent regarding genetic materials is even more complicated.

INTRODUCTION TO SESSION 4: The Relationship between Survey Participants and Survey Researchers

Stephen Blumberg, *National Center for Health Statistics*

Respondents' doubts about the personal or societal benefits of participation, concerns about privacy, and skepticism about promises of confidentiality are some of the numerous reasons for declining rates of participation in surveys. These increases in doubt, concern, and skepticism may be reflective of recent social transformations away from long-term contractual relationships. In her book *Shifts in the Social Contract*, Beth Rubin (1996) noted that a shift toward short-term contracts in society may result in reduced feelings of civic responsibility, more mistrust of outside entities, and less respect for the rights of the other parties in the contract. Do reduced feelings of civic responsibility reduce perceptions of the benefits of survey participation? Does more mistrust increase concerns about privacy and confidentiality? Does less respect increase treatment of respondents as "subjects" rather than "participants" and increase the possibility of ethical lapses in the treatment of respondents and their data? This session was developed with the premise that a careful consideration of changes over time in the implied contract between survey participant and survey researcher may help survey researchers understand respondent's concerns and increase the probability of response.

Trust and mistrust between interviewers and respondents are examined in two papers with very different methods. Koustuv Dalal reports on the challenges faced in the field when conducting a survey about violence against women in rural India. Illiteracy and low levels of education among respondents would be a challenge for any survey researcher, but these challenges were exacerbated by suspicion of outsiders by potential respondents and their political leaders. Social customs, traditions, and beliefs contributed to this suspicion.

Mick Couper and his colleagues conducted their research in a laboratory rather than the field, yet they also demonstrate the role that suspicion plays in survey participation decisions. Perceptions about confidentiality and privacy and the likelihood and magnitude of harm if others learned their responses were significant predictors of survey participation. Importantly, these perceptions were more important predictors of survey participation than objective information about confidentiality, privacy, and disclosure risk.

Promoting the establishment of mutual trust among survey researchers and respondents is the focus of the next two papers. Dianne Rucinski describes her community-based participatory survey research efforts in which members of the community to be surveyed help design, conduct, and interpret the results of surveys. When surveys that will benefit the community are planned and implemented with the community's assistance, members of the community may be more responsive when asked to complete the survey. Yet, as Rucinski notes, the values of a survey researcher are not always compatible with the values of a community.

Robin D’Aurizio approaches this same issue from the alternative perspective of a former field interviewer and trainer, but she also notes a conflict between survey researchers and community members. Respondents’ perceptions of the costs and benefits of survey participation differ from researchers’ understanding of the costs of doing surveys. D’Aurizio recommends approaching respondents as if they were potential customers for researchers’ products. “Sales” will be more likely, she suggests, if surveys are kept short and simple and if they appeal to the wants, needs, and fears of people today.

The latter part of the session consists of a paper by Roger Tourangeau and commentaries by several prominent survey researchers. Tourangeau provides a historical perspective on the relationship between the survey participant and the survey researcher, and he then offers several reasons why the path of history has led to today’s difficulties. Increased motivation to avoid unwanted intrusions on one’s time, the decline of civic engagement, and unintended consequences of incentives all receive attention in this invited paper.

REFERENCE

Rubin, B. A. (1996). *Shifts in the social contract.* Thousand Oaks, CA: Pine Forge Press.

FEATURE PAPER: Hurdles and Challenges of Field Survey for Collection of Health-Related Data in Rural India

Koustuv Dalal, *Karolinska Institutet*

INTRODUCTION

Violence against women is an important public health issue (Watts & Zimmerman, 2002; World Health Organization, 1998). A World Bank report estimated that violence against women is as serious a cause of death and incapacity among women of reproductive age as cancer and is a greater cause of ill health than traffic accidents and malaria combined (Heise, Pitanguy, & Germain, 1994).

Women’s health is one of the most neglected areas in India as far as research and policy making are concerned (Velkoff & Adlakha, 1998; The World Bank, 1996). A UN report shows that 70% of married Indian women between the ages of 15 and 49 are victims of beatings, rape, or coerced sex, and every day, 14 women are murdered by their husbands’ families (Menon-Sen & Kumar, 2001). Further, violence against women in India is a significant public health problem and leading socioeconomic burden (Heise et al., 1994; Menon-Sen & Kumar, 2001).

Violence against women in India is like the visible part of an iceberg, as the phenomenon is, if reported at all, underreported (Gumber, 1994; Guraraj, 2005). No multistate study—especially in rural areas—has been conducted at the government level in India to estimate the actual extent of violence against women and its impact on health. Recently, a survey was conducted in rural India to measure impact of violence against women and its socioeconomic and health consequences.

The survey was conducted for nearly two and half years in rural areas of seven Indian member-states: Andhra Pradesh, Bihar, Himachal Pradesh, Punjab, Orissa, Uttar Pradesh, and West Bengal. Due to illiteracy and lack of education among potential respondents, self-administration was not a feasible survey mode. Furthermore, it is already established that lower socioeconomic classes are underrepresented in surveys conducted via means other than face-to-face (Eastwood, Gregor, MacLean, & Wolf, 1996). For these reasons, the survey relied on face-to-face interviewing, although this mode is comparatively more expensive (O’Toole, Battistutta, Long, & Crouch, 1986). The initial sample size was 3,000 women.

Very few studies have been performed in India at the multistate level, and those have been confined mainly to city areas. This survey focused on rural Indian women, and collecting data from this population presented the designers and interviewers with numerous hurdles and challenges. The objective of this paper is to systematically identify those problems to aid future such studies.

METHODS

The particular areas of violence against women in India were identified through extensive literature reviews and media reports at the national level. Once this was done, we conducted a pilot test to determine if alterations to the questionnaire were needed.

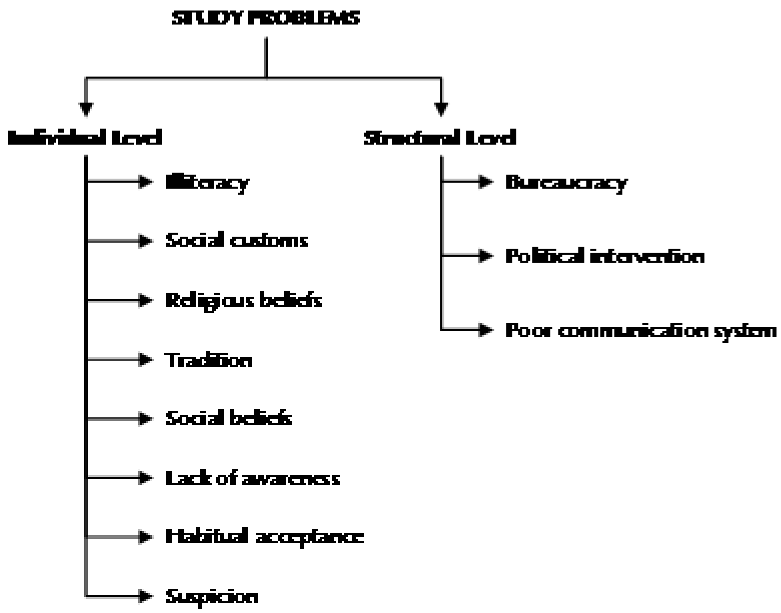
Relying on lessons learned from the pilot study, the questionnaires were revised and formatted, and interviewers were trained for the field interviews. Interviewers employed for the study had at least a bachelor's degree.

As the survey addressed women's health and confidential family matters, the interviewers initially described the study objective to prospective respondents. They also reiterated that the information gathered from the interview would be used strictly for research purposes and in no way would be disclosed to their peers, relatives, and/or friends. They then obtained informed consent and finally started the interviews. During interviews, the interviewers tried to maintain privacy so that other potential respondents could feel confident about the interviewers' motives.

The main family-level variables were number and gender of family members, highest education level of the family, family income, sex of the head of the family, sex of the primary income earner of the family, etc. Individual-level variables included respondent's education status, income, her regular contribution to family-level work, etc. To measure violence, the interviewers asked about type of violence (physical or psychological), whether reported violence was instrumental or noninstrumental, frequency of violence in the last 24 and/or 48 hours and previous week, the reasons for violence, sex of the perpetrator, sex of initiator (who insisted on or is responsible for the violent act), the health consequences and extent of violence, any physical or psychological complications due to violence, etc. The study also considered respondent religion and caste. Women from tribal societies also were considered in this study.

The final study questionnaire did not ask for the respondent's name. The pilot study showed that it was nearly impossible to convince women from the remotest villages to participate if their names were asked. During the main study, interviewers stressed to respondents that their names would not be asked or included in the study.

Figure 1. Problems of Women's Health Survey in Rural India



STUDY CHALLENGES

The interviewers faced many challenges in conducting the interviews. These challenges can be categorized broadly as individual-level and structural-level challenges (Figure 1).

Individual-Level Challenges

Illiteracy. Most rural women are illiterate and completely unaware of the nature, extent, and outcomes of their problems due to domestic violence, and many were reluctant to speak with interviewers about the issue, as they did not consider it a problem. Thus, the interviewers initially faced the challenge of convincing prospective respondents of the objective and purpose of the study. A great deal of interviewer time was invested in gaining consent to participate in the interview.

Social Customs. In rural areas of India, it is not customary for women, especially young women, to come out in front of outsiders. At the same time, women are not prepared to share family-level matters with even male members of their families. As outsiders, the female interviewers faced many hurdles in explaining the study's objective and persuading potential respondents to participate.

Religion. Among those with certain religious beliefs and in some tribal castes, it is believed that being beaten by a husband and/or senior male member of the family is a boon to the woman. Further, some believe that the particular parts of the body that are beaten will be prepared for heaven after death. These women told the interviewers that this was neither a problem nor a topic to be discussed. They did not participate in this survey.

Tradition. Most rural women do not think their health-related problems can be discussed with outsiders. They prefer to discuss such matters with senior female members, such as a mother or mother-in-law. Senior female family members reiterated that this is their family tradition. Such women could not be interviewed.

Beliefs. There are some remote areas in which women believe that any illness or anything wrong with the body is caused by a curse and can only be cured by God's willingness. For these women, the local priest's advice is most important; without the priest's intercession via hymn and/or herbal remedies, the ailing person has to suffer. Women from such areas did not participate in the survey.

Lack of Awareness. Some women were unaware of violence against women and of the possible consequences of domestic violence against them. The interviewers failed to convince those women that this is a serious problem of women. Those groups of women were excluded from this study.

Habituality. In most rural areas, women are habituated to accept the health consequences of violence. They know that in all stages of life, they socioeconomically depend exclusively on male family members (e.g., father, brother, husband). To state it superficially, they accept domestic violence as a survival strategy. When asked to participate in this study, they were not interested, as some of them replied that it could not change their fate and life. A few of these women ultimately did participate in the study.

Suspicion. In some rural areas, the socioeconomic and cultural atmosphere makes the women highly suspicious, particularly of outsiders; they believe that sharing information will lead to negative consequences. Interviewers discussed the survey topic with these women, and some agreed to be interviewed. But when they were asked about their health consequences and violence against women, they immediately declined to answer. They clearly suspected something bad would result from answering such questions. Despite much effort and time on the part of the interviewers, such women could not be included in the study.

Structural-Level Challenges

Bureaucracy. The Indian administrative system is hindered by its bureaucratic system. This survey faced many bureaucratic hurdles. Getting permission from the local authority (where applicable) to conduct the study was time consuming and required a great deal of man power. In some instances, gaining permission from the local authority took all of an interviewer's time.

Political Intervention. After gaining permission from the concerned authority when the survey was started, in some areas the interviewers faced many local political obstacles. Even when interviews had begun, local political leaders created hindrances. In some cases, the interviewers were compelled to stop the survey. As this survey was not being conducted by the government, the local leaders were suspicious and could not be persuaded to allow the survey.

Poor Communication System. In some areas, the interviewers suffered from lack of basic amenities. They walked several kilometres to reach to the tribal societies to conduct the interviews; after completing the interviews, they walked the same distance to return to their survey base station. In those areas, they did not have proper food and lodging. In instances of illness, they had to resort to self-medication. In some cases, the interviewers were denied a second visit in the remotest areas.

CONCLUSIONS

Most of the individual-level problems of this study are highly interrelated, but the factors underlying these problems are illiteracy and lack of education in rural India. The structural-level problems also can be viewed as a result of illiteracy and lack of education.

With increases in literacy and education, rural Indian women gradually should gain awareness of their own problems. This would make them more likely to participate in this sort of survey and also eliminate at least the first two of the structural problems—bureaucracy and political intervention.

Motivation to participate in survey research depends on complex factors (Groves, Cialdini, & Couper, 1992); those women who were persuaded of the importance and relevance of the study were highly motivated participants. Rural Indian women are unfamiliar with surveys and survey-related situations. Most of the tribal women in the remotest areas very rarely have the opportunity to talk to village outsiders, so they are unaware that their health-related issues or violence against them can be discussable matters. Through this survey, at least some women who discussed the matter (both those who did and those who did not participate) were left with new ideas about violence against women and their own health-related issues. Over time, these ideas are likely to spread amongst residents of these rural villages.

As suggested above, surveys of this nature have the potential to raise awareness among the women they seek to interview of the nature and consequences of violence against them, suggesting that future such surveys will have benefits far beyond the collection of data. However, conducting additional surveys such as the one described in these pages will require the involvement, assistance, and support of policy makers, political parties, and funders.

REFERENCES

Eastwood, B. J., Gregor, R. D., MacLean, D. R., & Wolf H. K. (1996). Effects of recruitment strategy on response rates and risk factor profile in two cardiovascular surveys. *International Journal of Epidemiology, 25,* 763–69.

Groves, R. M., Cialdini, R. B., & Couper, M. P. (1992). Understanding the decision to participate in a survey. *Public Opinion Quarterly, 56,* 475–495.

Gumber, A. (1994). *Burden of injury in India: Utilization and expenditure pattern.* Harvard University, Takemi Program in International Health Working Paper. Retrieved January 20, 2007, from www.hsph.harvard.edu/takemi/RP88.pdf

Gururaj, G. (2005, September). Injuries in India: A national perspective. In *Burden of disease in India* (pp. 325–347). NCMH Background Paper. New Delhi, India: National Commission on Macroeconomics and Health.

Heise, L. L., Pitanguy, J., & Germain, A. (1994). *Violence against women: The hidden health burden.* World Bank Discussion Paper. Washington>, DC: The World Bank.

Menon-Sen, K., & Kumar, A. K. S. (2001). *Women in India: How free? How equal?* Report commissioned by the Office of the Resident Coordinator in India, United Nations. Retrived May 9, 2007, from www.un.org.in/wii.htm

O'Toole, B. I., Battistutta, D., Long, A., & Crouch, K. (1986). A comparison of costs and data quality of three health survey methods: Mail, telephone and personal home interview. *American Journal of Epidemiology, 124,* 317–328.

Velkoff, V. A., & Adlakha, A. (1998). *Women's health in India.* Women in development. U.S. Census Bureau. Retrieved May 9, 2007, from www.census.gov/ipc/prod/wid-9803.pdf

World Health Organization. (1998). *Violence against women.* Geneva: WHO/FRH/WHD.

The World Bank. (1996). *Improving women's health in India*. Washington, DC: Author. Retrieved May 9, 2007, from www.worldbank.org/html/extdr/hnp/population/iwhindia.htm

FEATURE PAPER: Risk of Disclosure, Perceptions of Risk, and Concerns about Privacy and Confidentiality as Factors in Survey Participation[1]

Mick P. Couper, Eleanor Singer, Frederick Conrad, and Robert M. Groves, *University of Michigan*

INTRODUCTION

Concern about protecting the confidentiality of personal information disclosed to researchers, including health information, has led to increasing interest in what has come to be called statistical disclosure limitation (e.g., Doyle, Lane, Theeuwes, & Zayatz, 2001; Fienberg & Willenborg, 1998; Fuller, 1993; Jabine, 1993; Lambert, 1993; Raghunathan et al. 2003; Rubin, 1993). "Statistical disclosure" refers to the ability to deduce an individual's identity despite the absence of personal identifiers, such as name and address, on the data file, through a process of matching an individual's de-identified record against another record containing (some of) the same characteristics as the original file in addition to the person's name and address. Although successful matches have been reported (Malin & Sweeney, 2000; Paass, 1988; Winkler 1997), little is known about the likelihood of such disclosures from publicly available data files.

The research reported in the present paper is part of a research program aiming to estimate the risk (probability) of statistical disclosure in publicly available data sets and to develop procedures to reduce that risk. Our specific aim was to use this information about disclosure risk to craft informed consent statements.

Several studies have shown that concerns about privacy and confidentiality reduce participation in surveys, specifically the U.S. decennial censuses of 1980, 1990, and 2000 (Fay, Bates, & Moore, 1991; Hillygus, Nie, Prewitt, & Pals, 2006; Singer, Mathiowetz, & Couper, 1993; Singer, Van Hoewyk, & Neugebauer, 2003). In an experiment embedded in the Survey of Consumer Attitudes, a monthly telephone survey, Singer (2003) showed that subjective perceptions of disclosure risk and perceptions of harm from the disclosure of identified information are highly correlated with expressed willingness to participate in surveys described in vignettes.

Findings from two earlier laboratory experiments are reported in Conrad et al. (2006). In the current study, funded by NICHD, we broaden our focus to investigate, via a Web experiment, the effects of variations in the objective risk of disclosure and the sensitivity of survey topics, as described in vignettes, on expressed willingness to participate in hypothetical surveys and on the perceived risks and harms of doing so.

METHODS

Sample & Administration

The Web survey for the current study was administered by Market Strategies Inc. on a volunteer sample drawn from Survey Sampling International's Internet panel. We received 3,671 completed questionnaires.

Questionnaire

Each questionnaire included eight fictional survey invitations, or vignettes (described below) and questions about perceived risk of disclosure, harm from disclosure, and perceived personal and social benefits, which were administered to half the sample after the first vignette and to the other half after the eighth vignette. Additional items related to general privacy and confidentiality concerns, attitudes toward surveys, trust, preferences for having risks described in numbers or in words and perceived equivalences between numerical and verbal descriptions, background characteristics, and manipulation checks. The entire questionnaire took about 12 minutes to complete.

The vignettes varied three factors: the survey topic (two sensitive topics—sex and finances—and two nonsensitive topics—leisure activities and work status), the description of the risk of disclosure (no mention, no chance, one in a million, one in ten), and an assurance of confidentiality (included or not). Each vignette also mentioned the study's sponsor (the National Institutes of Health), a benefit statement (tailored to the topic), the interview length (20 minutes), and an incentive ($10); these features were kept constant across all 32 vignettes resulting from the complete crossing of Topic x Risk x Confidentiality. Each set of eight contained all four risk statements, one each for a sensitive and a nonsensitive topic, and either a confidentiality assurance or no assurance for all eight. The sets were randomly assigned to subjects after they agreed to participate, and the order in which the vignettes were administered was random within subjects.

Immediately after answering how likely they were to participate in the survey described, respondents were asked an open-ended question about the reasons for their decision. The first and second reasons given were coded independently by two coders; kappa for the first codes was 0.79 for reasons for participating (n = 264), and 0.84 for reasons for not participating (n = 836). Specific reasons also were grouped into major categories.

Variables Used in Analyses

In addition to those described above, the following variables were used in the analyses:

Willingness to participate. This variable was measured by a single question, asked immediately after the vignette had been read:

> *On a scale from zero to ten, where zero means you would definitely not take part and ten means you would definitely take part, how likely is it that you would take part in this survey?*

Perceptions of risk. Parallel items asked about four different groups: family members; businesses that might try to sell you something; employers; and law enforcement agencies like the IRS, the Welfare Department, or the police department:

> *How likely do you think it is that each of the following people or groups would find out your name and address, along with your answers to the survey questions? Please answer using a scale from zero to ten, where zero means they will never be able to find out your answers, and ten means they are certain to find out your answers.*

Answers to the four questions were summed and averaged for a general measure of perceived risk

(Cronbach’s alpha = 0.809).

Perceptions of harm. “Perception of harm” was measured by the following question, asked about the same four groups listed above:

> *How much would you mind if each of the following found out your name and address, along with your answers to the survey questions? Please use the same scale from zero to ten, where zero means you would not mind at all, and ten means you would mind a great deal.*

Answers were again summed and averaged (Cronbach’s alpha = 0.814).

Perception of benefits to self and society. ”Benefits to society” were measured by the following question, asked about four different groups—the government agency sponsoring the survey, businesses planning new products, other researchers, and law enforcement agencies:

> *On a scale from zero to ten, where zero means not at all useful and ten means very useful, how <u>useful</u> do you think each of the following groups would find the information from the survey described above?*

Answers to the four questions were summed and averaged (Cronbach’s alpha = 0.834).

“Benefits to self” were assessed by one question:

> *Would you, yourself, get anything good out of the survey?* (Yes, No)

Perception of risks vs. benefits. The risk-benefit ratio was measured by a question that asked

> *Taking it all together, do you think the risks of this research outweigh the benefits, or do you think the benefits outweigh the risks?* (Risks outweigh benefits, Benefits outweigh risks)

***General questions*. Following the vignettes and questions pertaining directly to them, respondents were asked a series of more general questions, some pertaining to general concerns about privacy and confidentiality and attitudes toward surveys. An exploratory factor analysis reduced these to two clear factors, one consisting of three questions tapping privacy concerns, the other of two multipart questions about attitudes toward survey organizations. Two other variables, measuring trust in people and in government, correlated 0.21 with each other but did not load highly on either factor; we combined these into a third index measuring trust.**

ANALYSIS & RESULTS

Unless otherwise noted, all analyses are based on responses to the first vignette only, to avoid being affected by exposure to multiple vignettes, and are further restricted to those who were aware of differences among the vignettes (75.9% of the sample). Thus, the analyses are based on a between-subjects design, using linear regression with maximum likelihood estimation (*N* = 1,359).

Confidentiality, Risk, & Sensitivity

Whether subjects received an assurance of confidentiality made no significant difference in their willingness to participate (WTP), nor did confidentiality interact significantly with either sensitivity of

topic or risk of disclosure. Accordingly, interaction terms have been omitted from Table 1.

Counter to our expectation, disclosure risk, as described in the vignettes, had no significant overall effect on expressed willingness to participate in the survey. The sensitivity of the topic, on the other hand, was highly significant, with leisure activities and work leading to higher levels of WTP than money or sex, the latter being the least likely to elicit agreement to participate. (Table 1 shows the effect for two levels of sensitivity only.) When the topic of the survey is sensitive, willingness drops by almost a full point on the 11-point scale: from 7.36 to 6.46.

Table 1. The Effect of Risk, Sensitivity, & Confidentiality Assurance on Willingness to Participate, First Vignette

Variable	Parameter Estimate	Standard Error
Intercept	7.3578	0.2283***
Risk: One in ten	-0.3018	0.2590
Risk: One in a million	-0.1510	0.2598
Risk: No chance	-0.2733	0.2595
Risk: No mention	-	-
Sensitivity	-0.8999	0.1844***
Confidentiality	-0.2054	0.1847

***$p < .001$. Model adj. $R^2 = 0.019$.

We replicated these basic analyses across all eight vignettes within person, using IVEware (Raghunathan et al., 2001; 2005) to account for the repeated measures within person. The model in Table 2 includes controls for the order in which the vignettes were presented (with later vignettes producing lower levels of WTP, on average) and whether the debriefing questions were asked after the first or eighth vignette (lower levels of WTP when debriefed early). Neither of these variables interacted with the key manipulations of interest. While the results generally mirror those in Table 1, the risk of disclosure has a statistically significant effect on WTP (*F* = 3.71, *df* = 3, 2,774; *p* < .05) in these analyses. When subjects see more than one vignette and when they are debriefed (as half the sample was after the first vignette), risk reaches conventional levels of significance. Examining specific contrasts, the one in ten risk is significantly different from one in a million (*t* = 10.5, *p* < .001) and from no chance (*t* = 16.8, *p* < .001), and one in a million is significantly different from no chance (*t* = 2.86, *p* < .05).

Risk, Sensitivity, Confidentiality, & Perceptions of Risk & Harm

The overall effect of risk of disclosure on subjects' *perceptions* of risk is significant (*p* = 0.014; Table 3; *F* = 3.56, *df* = 3, 1,354). When the risk of disclosure is described as one in ten, perceived risk is 3.93 on an 11-point scale; when it is described as one in a million, perceived risk is 3.32. Neither confidentiality assurance nor sensitivity of the topic has a significant effect on perceived risk.

Sensitivity of the topic has a significant effect on perceptions of harm: when the topic is not sensitive, perceived harm is 5.81 on an 11-point scale; when it is sensitive, perceived harm is 6.36 (*p* = .0004, *F* = 12.84*, df* = 1). Neither of the other variables is significant, nor are any of the interactions.

Table 2. The Effect of Risk, Sensitivity, & Confidentiality Assurance on Willingness to Participate, All Eight Vignettes

Variable	Parameter Estimate	Standard Error
Intercept	7.4819	0.09992***
Risk: One in ten	-0.4597	0.0413***
Risk: One in a million	-0.0148	0.0236
Risk: No chance	0.0957	0.0380*
Risk: No mention	-	-
Sensitivity	-1.2437	0.0418***
Confidentiality	-0.0988	0.1109
Vignette number	-0.0535	0.0068***
Debriefed after V1 (1=yes)	-0.3253	0.1110**

$^{**}p < .01$; $^{***}p < .001$. Model adj. $R^2 = 0.038$.

Perceptions of Risk & Harm & Willingness to Participate

In earlier research, Singer (2003) found that subjective perceptions of risk and harm were highly correlated with WTP. However, neither objective risk nor topic sensitivity was systematically varied in that study. As in the earlier study, both variables were significantly correlated with WTP in the present study: the lower the perceptions of risk and harm, the higher the WTP, controlling for sensitivity, objective risk, and confidentiality.

General Attitudes toward Privacy, Confidentiality, & Surveys

Table 3 shows the relationship of general attitudes toward privacy, surveys, and trust to WTP, controlling for objective risk, sensitivity, and confidentiality. The coefficients for privacy concerns and attitudes toward surveys are significant, while that for trust is marginally significant (*p* = 0.06). The increase in variance explained by the three general attitudes over a model containing the experimental variables only is significant and similar to that produced by adding subjective perceptions of risk and harm to the basic model: from an adjusted R^2 of 0.0156 for the basic model to an adjusted R^2 of 0.0714 when attitudes toward privacy, surveys, and trust are added to the equation, compared with an increase in R^2 to 0.0649 for a model adding perceived risk and perceived harm to the basic model. When both sets are included, R^2 increases significantly to 0.0909.

Table 3. The Association of Risk, Sensitivity, Confidentiality, Privacy Concerns, Attitudes toward Surveys, & Trust with Willingness to Participate, First Vignette

Variable	Parameter Estimate	Standard Error

Intercept	7.1731	0.2389***
Risk: One in ten	-0.2495	0.2519
Risk: One in a million	-0.1280	0.2527
Risk: No chance	-0.2330	0.2522
Risk: No mention	-	-
Sensitivity	-0.9168	0.1792***
Confidentiality	-0.2344	0.1795
Privacy concerns	-0.4269	0.0959***
Attitudes toward surveys	0.6064	0.0973***
Trust	0.2518	0.1356^{+}

***$p < .001$; $^{+}p = .06$. Model adj. $R^2 = 0.077$.

The Role of Benefits in the Participation Decision

Statements about personal benefits (a $10 incentive) and social benefits (NIH's use of the research results to formulate policy in various areas) also were included in the vignettes but not experimentally varied. Thus, three additional variables—perceived personal benefits, perceived social benefits, and respondents' estimated risk-benefit ratio, described in the Methods section—were available for analysis. As in earlier research (Singer, 2003), these three variables are powerful correlates of willingness to participate, and the explained variance in WTP increases from 0.0909 for the model without these three coefficients to 0.3709 for the model including them (*F* = 194.72, *df* = 3, 1,317; *p* < 0.0001).

Reasons for Participation Decision

After indicating how likely they were to participate in the survey that had just been described to them, respondents were asked an open-ended question probing the reasons for their decision. The discussion here is based on answers to the first vignette only; the distribution of codes did not differ significantly between the first and the last vignettes. Responses were divided into reasons for participation (scores of 6–10 on the 11-point scale) and reasons for nonparticipation (scores of 0–5). Some 67% of the 1,552 respondents who answered the question about reasons for participating had scores of 6–10 on the 11-point scale. The reasons they gave for being likely to participate in the study described were coded into three large groupings: altruistic reasons (30.3% of those responding to the question), egoistic reasons (33.6%), and reasons related to survey characteristics (26.6%); 5.2% of the responses were coded simply as "no objection." Only 3.3% of respondents gave what we called "general" reasons for not wanting to take part. The most frequent category of objections was that related to privacy concerns (47.4%), but only 3.3% referred specifically to the risk of disclosure, of someone's finding out their answers or name, or to a lack of security or chance of exposure. Somewhat over a quarter of the sample objected to some aspect of the survey other than privacy. An additional 13.4% made some negative reference to the survey topic, and almost 4% specifically said they would want more money to do the survey described.

LIMITATIONS & CONCLUSIONS

The study has a number of limitations. In particular, this is a study asking about hypothetical situations among a group of volunteer subjects who, by definition, are participating in a survey. However, the focus of the study was on examining the effects of the experimental manipulations rather than on estimating the actual level of participation in a sample of the general population.

Despite these limitations, we have learned a number of things from our experiments so far. These can be summarized as follows:

1. **Except under conditions that make disclosure risk salient, either by providing a frame of reference or by restricting the sample to those most sensitive to risk information, a description of the objective risk of disclosure does not reduce willingness to participate. When participants are exposed to one vignette only, objective risk is not significant; when they are exposed to eight vignettes varying the risk of disclosure, objective risk has a significant effect both in the laboratory and on the Web. Descriptions of disclosure risk also significantly affect subjective perceptions of risk.**
2. **Topic sensitivity has a consistent significant negative effect on willingness to participate as well as increasing perceptions of harm.**
3. **Perceptions of risk and harm have a consistent significant negative association with willingness to participate.**
4. **General attitudes toward privacy, surveys, and trust also influence willingness to participate as well as actual participation.**
5. **None of these variables explain a great deal of the variation in responses to the willingness-to-participate question; for that to occur, we believe respondents must perceive benefits from their participation as well as reductions in harms.**

We currently are planning another set of Web experiments to test some hypotheses growing out of the current set of results. Thus, we plan to look at the effect of varying the probability of harm from disclosure, rather than just the likelihood of disclosure; at the effect of making privacy issues salient for the respondent; and at respondents' willingness to trade risk for benefit. Ultimately, we plan to test our hypotheses in a general population sample.

REFERENCES

Conrad, F., Park, H., Singer, E., Couper, M. P., Hubbard, F., & Groves, R. M. (2006, May). *Impact of disclosure risk on survey participation decisions.* Paper presented at the 61st Annual Meeting of the American Association for Public Opinion Research, Montreal.

Doyle, P., Lane, J. I., Theeuwes, J. J. M., & Zayatz, L. V. (Eds.) (2001). *Confidentiality, disclosure, and data access: Theory and practical applications for statistical agencies.* Amsterdam: North Holland/Elsevier.

Fay, R. L., Bates, N., & Moore, J. (1991). Lower mail response in the 1990 Census: A preliminary interpretation. In *Proceedings of the Annual Research Conference* (pp. 3–32). Washington, DC: U.S. Bureau of the Census.

Fienberg, S. E., & Willenborg, L. C. R. J. (1998). Introduction to the special issue: Disclosure limitation methods for protecting the confidentiality of statistical data. *Journal of Official Statistics, 14*(4), 337–345.

Fuller, W. A. (1993). Masking procedures for microdata disclosure limitation. *Journal of Official*

Statistics, 9, 383–406.

Hillygus, D. S., Nie, N. H., Prewitt, K., & Pals, H. (2006). *The hard count.* New York: Russell Sage.

Jabine, T. B. (1993). Statistical disclosure limitation practices of United States statistical agencies. *Journal of Official Statistics, 9,* 427–454.

Lambert, D. (1993). Measures of disclosure risk and harm. *Journal of Official Statistics, 9,* 313–331.

Malin, B., & Sweeney, L. (2000). Determining the identifiability of DNA database entries. In *Proceedings, Journal of the American Medical Informatics Association* (pp. 537–541). Washington, DC: Hanley & Belfus, Inc.

Paass, G. (1988). Disclosure risk and disclosure avoidance for microdata. *Journal of Business and Economic Statistics, 6,* 487–500.

Raghunathan, T. E., Lepkowski, J. M., Van Hoewyk, J., & Solenberger, P. (2001). A multivariate technique for multiply imputing missing values using a sequence of regression models. *Survey Methodology, 27*(1), 85–95.

Raghunathan, T. E., Lepkowski, J. M., Van Hoewyk, J., & Solenberger, P. (2005). *IVEware, a software for the analysis of complex survey data with or without multiple imputations.* Ann Arbor: University of Michigan, Institute for Social Research.

Raghunathan, T. E., Reiter, J. P., & Rubin, D. B. (2003). Multiple imputation for statistical disclosure limitation. *Journal of Official Statistics, 19,* 1–16.

Rubin, D. J. (1993). Discussion: Statistical disclosure limitation. *Journal of Official Statistics, 9,* 461–468.

Singer, E. (2003). Exploring the meaning of consent: Participation in research and beliefs about risks and benefits. *Journal of Official Statistics, 19*(3), 273–285.

Singer, E., Mathiowetz, N., & Couper, M. P. (1993). The impact of privacy and confidentiality concerns on Census participation. *Public Opinion Quarterly, 57,* 465–482.

Singer, E., Van Hoewyk, J., & Neugebauer, R. (2003). Attitudes and behavior: The impact of privacy and confidentiality concerns on participation in the 2000 Census. *Public Opinion Quarterly, 65,* 368–384.

Winkler, W. E. (1997). *Views on the production and use of confidential microdata* (Statistical Research Report 97/01). Washington, DC: U.S. Census Bureau.

[Note 1] We thank NICHD (Grant #P01 HD045753-01) for support and John Van Hoewyk for indispensable help with analyses. We also thank Rachel Orlowsky and Catherine Millitoe for coding the open-ended responses.

[Note 2]Significance levels for the variables in Tables 1, 2, and 3 and their two-way interactions were estimated using the GLM procedure in SAS. Since none of the interactions was significant at the 0.05 level, only the three independent variables are shown.

FEATURE PAPER: Community-Based Participatory Research and Survey Research: Opportunities and Challenges[Note]

Dianne Rucinski, *University of Illinois at Chicago*

In recent years, there has been considerable attention to understanding the factors that lead respondents to participate or decline to participate in surveys, and some of this work has focused on considering the relationship between respondents and survey researchers. This relationship may take on additional complexities and meanings when the research involves the use of a *community-based participatory research* (CBPR) approach. CBPR is applied most frequently in health and environmental research and has been defined as a "…collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change" (Viswanathan et al., 2004, p. 22).

Many claims have been made about potential benefits of using CBPR, such as promoting the establishment of mutual trust among researchers and the community and fostering an enhanced understanding of a community's special circumstances and the unique conditions that would inhibit or foster the success of an intervention (Shulz et al., 1997; Butterfoss, Goodman, & Wandersman, 1993). The use of CBPR in health promotion and prevention research may increase the probability of successful health interventions because the research begins with the community, is assisted by the community, and, if successful, will benefit the community, and hence, the community is more receptive to the intervention (Minkler & Wallerstein, 2003). Government support for CBPR approaches is found in funding opportunities such as the National Institute for Environmental Health Sciences (NIEHS) program "Community-Based Prevention Intervention Research" and the Centers for Disease Control's Urban Centers for Applied Research in Public Health. There is also substantial private support for CBPR initiatives, such as the W.K. Kellogg Foundation's "Community-Based Public Health." Increasingly, CBPR approaches are used in health services research and environmental health research and thus have increased relevance for students of health survey methods (Viswanathan et al., 2004). This is especially true in health disparities research, where there continues to be a gap between knowledge generated through social research and the translation of the research into practices, interventions, and policies designed to reduce and eliminate health disparities among minorities and economically disadvantaged populations (Kaplan, 1991; Mittlemark, Hunt, Heath, & Schmid, 1993).

One of the fundamental concepts of community-based participatory research is that the community and research entity function in partnership to design, implement, and interpret the results of research investigations. Minkler (2005) suggests that CBPR contributes "added value" to health research. Some of these benefits have been applied to discussions of CBPR and survey research methods. They include developing research questions that are of genuine concern to the community; improving cultural sensitivity and reliability of measurement instruments and enhancing the accuracy of data interpretation and cultural sensitivity (Brown, 2004; Cornelius et al., 2004; Call et al., 2004); improving recruitment/retention efforts by increasing trust and ownership (Cornelius et al., 2004; Kaplan, Dillman, Calman, & Billing, 2004); improving the ability to get truly informed consent; expanding "benefits" of the research beyond the individual to the community; and increasing the relevance of intervention approaches and likelihood of success.

The use of survey research as a method presents a distinct set of challenges and opportunities for most CBPR enterprises, especially for those community-based organizations (CBOs) embracing social justice and equality as central to their missions. While many of the conventions of survey research methods are consistent with those democratic and egalitarian impulses, others are not. To illustrate how survey research methods were used and issues reconciled by community-university collaborators to assess whether planned interventions had the desired impact, I will focus on a project involving two cases that illustrate some of dynamics of using a CBPR approach, specifically those involving the mutual influences of survey processes on CBOs and their interventions and of CBOs and their interventions on survey processes.

BACKGROUND OF PROJECTS

The CBPR project under discussion here involved three community partners and one university research partner. The Healthy Schools Campaign (HSC), a 501(c)(3) organization with the mission of improving health through changing the school health environment received a NIEHS grant to fund the "Partnership to Reduce Disparities in Asthma and Obesity in Latino Schools." In this four-year project, HSC worked closely with two community-based organizations —West Town Leadership United (WTLU) and Little Village Environmental Justice Organization (LVEJO)—to develop effective community-driven strategies that address the problem of asthma and obesity in school and community environments. In both communities, children are more likely to suffer from asthma and obesity than children in non-Hispanic White communities (Whitman, Williams, & Shaw, 2004). As CBPR projects, the WTLU and LVEJO each selected their own health topic for focus and intervention with support from HSC. WTLU selected asthma as their targeted health topic, and LVEJO selected pediatric overweight/obesity rates.

CASE 1: West Town Leadership United

WTLU's uses what it terms a "Family-Focused Leadership and Organizing" model to build its organization and to accomplish its goals. As a grassroots community organization dedicated to social justice, WTLU stresses the importance of community leadership emerging within its ranks through education, communication, and community action.

For their intervention, WTLU decided that the best way to reduce asthma in the community was to locate a school-based health clinic in one of the neighborhood schools. Based on their experience (discussed below), they believed that members of the community lacked access to health care services due to low incomes, high rates of uninsurance, immigration status, and logistical issues, despite the availability of a county clinic that serves people regardless of insurance and documentation status located within two miles of the community. WTLU believed that many children and adults lacked a medical home and that with a school-based clinic, increased access to health care and utilization would improve health. Furthermore, WTLU argued that to be of maximum benefit to the community, the school-based clinic should serve members of the community, regardless of their status as parents or not. In other words, the target of the intervention was not only students and their parents, but all residents in the community needing health services.

The full team of three CBOs and the university partner determined that a pre-post design employing community surveys would be the best approach to capture changes in access to health care and utilization attributable to a new school-based clinic. The pre-post survey instrument draft began with an eleven-item questionnaire that WTLU was using at the time for community organizing purposes. This community survey included general questions about health and asthma, as well as items about medical debt. It also included a question to gauge the respondent's interest in joining WTLU's "campaign for health care for all" and requested contact information (i.e., name, address, and phone). The revised questionnaire—following interactions with the university partners—included 47 items, including standardized questions about health insurance, access to and utilization of health care services, delaying/avoiding treatment due to ability to pay, medical debt, denial of care, and presence of acute health conditions. In addition, the revised instrument eliminated the question about whether the respondent would participate in a "campaign to get health care for all" and the respondent-identifying contact information. This revised questionnaire targeted a randomly sampled adult and the youngest child in a family for a series of health access and utilization questions. Finally, the new protocol employed an informed consent process to inform respondents of the purpose of the study, their rights as respondents, potential risks and benefits, and the limitations on our ability to protect information. In short, collaboration of the CBO and the university partner changed the questionnaire from a community-organizing tool to an instrument designed to capture change in community health care access and status.

As a CBPR project, defining the role of the community in a survey research project involved building in protocols that developed strengths and resources within the community. For that reason, a "soup-to-nuts" philosophy was employed to engage WTLU in data collection procedures. Discussions between the CBO and the university partner determined that all members of the partnership, including interviewers from WTLU, should be fully trained in the protection of human subjects as well as in project-specific matters, such as area probability listing and sampling, interviewing, and field management. The decision to engage community members as investigators and thus in all aspects of IRB-mandated training on the protection of human subjects contrasts with a more limited and tailored approach to human subjects protection provided to interviewers in other survey projects. In practice, the required training resulted in the loss of several active WTLU members as potential interviewers. Many did not have the computer skills necessary to feel comfortable completing an online training program designated by the university for gaining IRB certification for Spanish dominant research staff, nor did many have e-mail addresses that were required to demonstrate that they had completed training. Apart from the basic computer skills, the language used in the training program assumed a level of education was not consistent with members of the WTLU interviewing team. The frustration that many felt with the computers and the lack of availability of IRB training in everyday Spanish led some prospective interviewers to decline participation in data collection. Thus, the aim of upgrading the research capabilities of the CBO traded off against some members' participation in the project.

As noted, WTLU was familiar with and frequently used "surveys" to recruit members for the CBO and their social/political action campaigns. Research codes of ethics (e.g., AAPOR's *Code of Professional Ethics and Practices*) strictly prohibit the use of surveys for selling and fundraising, and, by extension, for building organizations. Initially, for WTLU, "the legitimacy and credibility of the scientific research process" was less a priority than the issues of social justice they were pursuing. After much discussion about the role and uses of survey research—specifically focused on "sample representativeness"—the CBO leadership understood how this survey would be different, and why the research product would be better if scientific procedures were pursued.

The CBO was initially reluctant to use probability sampling because they had been successful in recruiting convenience samples in community organizing. Through much discussion of the concept of "bias" and random sampling and with encouragement of all partners, the CBO agreed to use systematic random sampling of census tracts, blocks, and respondents within households to achieve a probability sample. In discussions and in trainings with staff members, the major point emphasized by the CBO partners was that using a sampling method that provided each person within a house with a chance of being selected was "fair." To an organization committed to equity and social justice, an approach that would give everyone a "fair" chance of taking part in the survey corresponded with their mission and values. Interviewers were trained using a Kish table. However, in the field, when CBO interviewers could not interview willing participants who had not been randomly selected, it seemed unfair that the sampling process would "take away the voice" of people who had something to say and were willing to be interviewed. That the research process would consciously exclude people who wanted to participate was viewed by some as anti-democratic and exclusionary, conflicting with WTLU's values and mission.

In the CBPR literature, it has been noted that as members of the community, CBO interviewers would be savvy about reaching potential respondents and respondents would be more likely to trust fellow residents (Kaplan et al, 2004). While this may be true and useful for studies using nonprobability methods of selection or operating in more homogeneous communities, it is not necessarily the case for those using probability methods or involving heterogeneous communities. Specifically, CBO interviewers became concerned when many respondents selected through area probability sampling were not Latino, or had higher incomes, or had health insurance. It was felt that these individuals did not represent "their" community nor did they reflect those WTLU members encountered in the convenience samples for their organizing efforts. These facts emerged despite the fact that the CBO drew the map defining their community within the area known as West Town. Members of WTLU were well aware that the West Town community was changing and gentrifying, but the extent of these changes were not apparent until the field operation was nearly completed.

Again, while the CBPR literature emphasizes the advantage of community interviewers possessing specialized knowledge that would permit them to find potential respondents through social or demographic similarity or other familiar community markers (i.e., West Towner to West Towner), there is a potential problem with recruiting a sample that has a specialized interest in the topic of a survey or the group conducting the survey. Groves (2006) asserts that differentially activating sub-segments of a sample may result in a higher response rate but a *more* rather than less biased sample.

The labor-intensive process of listing units, enumerating, and sampling within household units proved to be a greater effort than the CBO expected. Initially, only active members of the CBO were interviewers. The data collection period continued beyond the CBO's expectations and led to the recruitment by the CBO of college students to conduct the interviews because the survey work conflicted with their other organizing efforts. That is, when the survey ceased to serve the dual function of gathering information and recruiting new members/ac-tivists to WTLU, the ability to commit people to the survey process declined. At this stage, paid professional interviewers were hired to help complete data collection.

Despite the challenges WTLU faced in conducting an area probability survey, conducting the survey did alter their perspective of who lived in the community—it was less Latino and higher income than originally thought. Thus, WTLU saw a different need based on those results. Instead of working to locate a school-based clinic that provided only basic medical services, the pretest data collection efforts led the WTLU to believe that the clinic should broadly focus on illness prevention rather than treatment of asthma and other acute conditions. From a public health perspective, the function of the survey may have been realized, albeit complicating forthcoming evaluation of the intervention, since the objectives of the intervention changed.

CASE 2: Little Village Environmental Justice Organization

LVEJO uses a *popular education model* (Freire, 1970) to build its organization and to accomplish its goals. Popular education is an educational approach used to make participants more aware of how the individual's experiences are connected to larger social issues. LVEJO's mission is to "work with families, coworkers, and neighbors to improve the environment and lives in the community of Little Village and in the city of Chicago through democracy in action" (LVEJO, 2007). For their intervention, LVEJO elected to attempt to change the type and quality of foods that are offered at local elementary schools. LVEJO members and local parents were concerned that the federally subsidized school breakfast and lunch programs did not provide healthy food options, and the healthy options that were offered were prepared in unfamiliar or unattractive ways. For example, chicken was often breaded and/or fried instead of being prepared as chicken rojo or enchiladas suiza. Tortillas were made with flour rather than with more healthy and culturally appealing base of corn. Parents reported to LVEJO that children, once acclimated to the American way of eating breakfast and lunch, were rejecting healthily prepared Mexican dishes at home. Thus, the intervention was intended to increase the amount of healthy food offered and increase representation of Mexican cuisine in the school menu.

A pre-post design was agreed upon by the CBO and university partner, and several evaluation methods were discussed, including "plate waste" studies, content analyses of menus, and interviewer-assisted food diaries. That the school system's internal timeline for approving a research proposal exceeded the timeframe covered in the grant and that the school system declined to provide the research team with copies of the menus made assisted food diaries the only viable alternative. The food diary involved a structured interview asking children age 7–11 to report what was served at breakfast and lunch over a three-day period.

LVEJO's embrace of the popular education model influenced the survey process in several respects. First, the design of the instrument went through several iterations, beginning with the research team's initial survey with 10 suggested questions (e.g., What kind of fruit was served at lunch today? [Prompts: bananas, apples, pears, or something else?]) with follow-up questions (e.g., Was it fresh fruit or not fresh? Did you eat all of it, some of it, or none of it? Was it good or not good? Tell me what you didn't like/liked about it) to the second version survey with 147 items suggested by the parent group in response to the initial survey to the final version with 32 items. The parent group wanted very precise information about what was served. However, through their own experiences in conducting a pilot test, the parent interviewers discovered that many children had a very difficult time drawing the kinds of distinctions the more detailed instrument required. The team discussed issues of data quality and respondent burden experienced by the interviewers during the pilot test, and the final, much reduced instrument was adopted. In this instance, the role of the researcher as an "expert" was less relevant to the CBO's process and organizational model than was the experience of piloting the instruments.

The popular education model also informed the research protocol in the informed consent and child assent components. As originally conceived, the assisted food diary protocol involved parent LVEJO interviewers interviewing their own children and also delivering the assent forms to their own children. In addition to the same barriers to IRB training experienced by WTLU interviewers, the internal university IRB review process declined to approve the protocol because children could not be expected to (a) freely consent without pressure from their parents and (b) honestly respond to questions about what they had eaten to their parents. Part of the consciousness-raising and experiential process of the popular education model used by LVEJO required that parents themselves conduct the survey with their children. Parents were not only uncomfortable interviewing other people's children but also did not want other parents interviewing *their* children. In the end, a compromise was reached that stipulated that the child assent process be administered by one of two widely known and respected LVEJO leaders. If children assented, their parents conducted interviews of their own children. This compromise allowed parents to learn—through personal experience—about what their children were served and were eating and allowed children to choose to participate with an adult other than their parent. Some parents were surprised to learn that many of their children were not eating the breakfast or lunches at all. The survey process led to further dialogue between parents and children about food and nutrition, which corresponds to the LVEJO popular education model.

CONCLUSION

In weighing the costs and benefits of using a CBPR approach with survey research methods, it is useful to consider results both in terms of the shared goals of CBPR and of survey research methods. In both cases described here, CBPR contributed to the development of research questions that were of real interest to each community group—the CBOs selected the health topics and collaborated with the other partners to select the method. Second, it is likely that the approach contributed to the cultural sensitivity and reliability of measurement instruments (though this also might have been achieved through careful pre- and pilot testing). In terms of improving recruitment/retention efforts by increasing trust and ownership, the evidence is mixed and conflicts with other goals of the research process. Specifically, if employing community interviewers increases participation among those who feel an affinity with the organization or interviewers or among those who share social characteristics with interviewers, using the CBPR approach could lead to a biased sample. Also, fielding an area probability survey can conflict with other organizational goals (including participants who are willing to be interviewed but are not sampled). In the case of WTLU, the cost of fieldwork increased as additional staff members were hired to replace organization members who were unable to continue working on the survey due to other organizational priorities. It is also not clear that the CBPR approach improved the ability to get truly informed consent. To date, the "capacity building" component of CBPR involved only IRB training and data collection techniques. It is likely that these skills are valued more by the university partners than by the community-based organizations. On the other hand, the use of CBPR did appear to enhance the utility of health interventions in these cases. Responding to the survey, one organization modified its intervention to focus more on health promotion and prevention and the other employed the survey to further raise the consciousness and resolve of members.

For the survey research community, in addition to the potential gains mentioned above, CBPR provides an educational outreach mechanism. It is clear that many organizations, such as the partners in this project, routinely try to use the tools of social sciences, especially surveys and focus groups, in their day-to-day practices. As noted earlier, the primary goals of using surveys for these groups is not to collect unbiased data for producing estimates or describing populations but rather to build organizations and/or raise consciousness. Because of these goals, important practices of survey research are not considered and, in some cases, were not known by the organizations profiled here. Since the adoption of best practices and ethical standards to enhance the quality of data and to protect human subjects is a key mission of the survey profession, survey researchers can invite organizations like these to attend our conferences and provide them with guidelines. Survey researchers also can actively engage with partners currently using survey methods in more interactive, responsive and, perhaps, a more effective way through CBPR approaches.

REFERENCES

Bloom, B., Dey, A. N., & Freeman, G. (2006). Summary health statistics for U.S. children: National Health Interview Survey, 2005 (DHHS Publication No. 2007-1559). *Vital Health Statistics, 10*(231).

Brown, E. R. (2004). Community participation and community benefit in large health surveys: Enhancing quality, relevance, and use of the California Health Interview Survey. In S. B. Cohen & J. M. Lepkowski (Eds.), *Eighth conference on health survey research methods* (pp. 49-54). Hyattsville, MD: National Center for Health Statistics.

Butterfoss, F. D., Goodman, R. M., & Wandersman, A. (1993). Community coalitions for prevention and health promotion. *Health Education Research, 8*, 526-536.

Call, K. T., McAlpine, D., Britt, H., Cha, V., Osman, S., Suarez, W., et al. (2004). Partnering with communities in survey design and implementation. In S. B. Cohen & J. M. Lepkowski (Eds.), *Eighth conference on health survey research methods* (pp. 61-66). Hyattsville, MD: National Center for Health Statistics.

Cornelius, L. J., Arthur, T. E., Reeves, I., Booker, N. C., Morgan, O., Brathwaite, J., et al. (2004). Research as a partnership with communities of color: Two case examples. In S. B. Cohen & J. M. Lepkowski (Eds.), *Eighth conference on health survey research methods* (pp. 55-60). Hyattsville, MD: National Center for Health Statistics.

Freire, P. (1970) *Pedagogy of the oppressed.* New York: Seabury Press.

Groves, R. M. (2006). Nonresponse rates and nonresponse bias in household surveys. *Public Opinion Quarterly, 70,* 646-675.

Kaplan, C. D. (1991). What works in drug abuse epidemiology in Europe. *Journal of Addictive Diseases, 11,* 47-59.

Kaplan, S. A., Dillman, K., Calman, N. S., & Billings, J. (2004). Opening doors and building capacity: Employing community-based approach to surveying. *Journal of Urban Health, 81*, 291-300.

Little Village Environmental Justice Organization. (2007). *Little Village Environmental Justice Organization welcomes you!* Retrieved June 8, 2007, from www.lvejo.org/

Minkler, M. (2005). Community-based research partnerships: Challenges and opportunities. *Journal of Urban Health, 82*(Supplement 2), ii3-ii12.

Minkler, M., & Wallerstein, N. (2003). *Community based participatory research for health*. San Francisco: Jossey-Bass.

Mittlemark, M., Hunt, M., Heath, G., & Schmid, T., (1993). Realistic outcomes: Lessons from community-based research and demonstration programs for the prevention of cardiovascular disease. *Journal of Public Health Policy, 4,* 437-462.

Schulz, A. J., Parker, E. A., Israel, B. A., Becker, A. B., Maciak, B. J., & Hollis, R. (1998). Conducting a participatory community-based survey for a community health intervention on Detroit's east side. *Journal of Public Health Management and Practice, 4*, 10-24.

Viswanathan, M., Ammerman, A., Eng, E., Gartlehner, G., Lohr, K. N., Griffith, D., et al. (2004). *Community-based participatory research: Assessing the evidence* (AHRQ Publication 04-E022-2). Evidence Report/Technology Assessment No. 99 (Prepared by RTI—University of North Carolina Evidence-Based Practice Center under Contract No. 290-02-0016). Rockville, MD: Agency for Healthcare Research and Quality.

Whitman, S., William, C., & Shaw, A. (2004). *Sinai Health System's community health survey report 1.* Chicago: Sinai Health System.

[Note] This research was supported in part by NIEHS grant #R25ES013207, and the research protocol discussed herein was approved by UIC IRB 2006-0027 and 2006-0292. The contents are solely those of the author and do not represent the views of the National Institute for Environmental Health Sciences.

FEATURE PAPER: A View from the Front Lines

Robin Brady D’Aurizio, *RTI International*

INTRODUCTION

It’s a complicated world. Field interviewers interact with that reality on a daily basis. Interviewer notes illustrate how the stresses of busy, complicated lives may impact the interviewer-respondent relationship from the start.

The **direct refusal**:

- “A black woman opened the door and said in an angry tone, ‘I asked you to take me off your list. Do it!’”
- “Same lady [who refused before] told me not to be so damned stubborn.”
- “Woman said it was not a good time to take survey. Housing unit contained strong smell of marijuana.”
- “Very rude man with a big dog asked me to go away. I never had a chance to say anything.”

The **silent rejection**:

- “Chinese man says ‘No’ with his finger.”
- “Opened the door, looked at me and shut the door in my face. I couldn’t say one word.”

The **gatekeeper intervention**:

- “Building manager told me to stop bothering his tenants or he’ll have me arrested.”
- “Started interview with young man. All of a sudden his mother comes out saying they want nothing to do with anything...or any survey and closed the door.”
- “Started interview [with respondent] and older brother says ‘no more questions’ and shut the door in my face.”

The **paranoid put-off**:

- “Spanish speaking male became suspicious when asked for his name and said he would not answer any more questions and shut the door."

- "Woman refused and stated her husband refused the night before. They called the police." (The residents blocked the interviewer's car in the driveway and demanded that he stay until the police arrived.)

The **"vicissitudes of life" blockade**:

- "Neighbor stated the FBI came the other day, raided the housing unit, and took the resident away to federal prison."
- "Wife began screaming at her husband and a fight broke out. I was told to leave 'right now!'"

The **busy/overwhelmed respondent sidestep**:

- "Respondent was holding a child who urinated on him. He said, 'I have to go,' and quickly shut the door.'"
- "Woman said 'I'm sorry but I just got out of work after working 36 hours, some other time.' She still had her blue hospital pants on."

The **"What's in it for me?" rejection**:

- "Woman asked what *she* would get out of taking survey, yelled an obscenity, and slammed the door."

The **language barrier**:

- "Security accompanied me to apartment. Older female opened door and repeated in very heavy Russian or Middle Eastern accent, 'I don't hear, I don't hear.'"

The **environmental hazard**:

- "A big fight broke out in front of building. Two men were beating up a younger guy. I did not go in."

> "No Trespassing sign, guard dog sign, guard dog, and a 'Beware of Owner' sign with a picture of a gun."

A GROWING RESISTANCE

The best minds in survey research work intensively to bring a study to the field. The client delineates the parameters of the study; mega-hours are consumed by instrument design; cost-benefit compromises are negotiated; IRB obstacles are addressed; incentives are debated; equipment is purchased; manuals are written; interviewers are trained; advance are letters mailed. The final product is a major achievement in study design and implementation.

Then, an interviewer knocks on the door of the respondent and the Chinese man says "No" with his finger. He seems to know in advance that he's not having any of what we're "selling."

The full measure of a study's success depends on its "delivery system." To borrow from business terminology—when the product is delivered to consumers, will they buy it?

Several factors are contributing to a real-world environment that is resistant to the goals of data collection. Our interview subjects are busier than ever; further, they are tuned in to a media culture that hypersaturates coverage of negative events and how-to solutions. People are coached in print and on television to take charge of their time and their lives. As a result, people are cautious, if not downright suspicious; gated communities and security-protected residences are on the rise; caller-ID and answering machines dominate; and people are better versed in the language of refusal.

A growing number of individuals are better at avoiding unsolicited contact altogether. According to an Associated Press article in *The Buffalo News* (January 21, 2007, by Will Lester):

> *The number of Americans with traditional landline telephones has declined sharply over the past three years—a trend with ramifications for phone surveys that inform policy and market research.*

The article further noted that the Centers for Disease Control and Prevention collected data in its National Health Interview Survey that has implications for the health survey research field: In the first half of 2006, one in eight households did not have a landline telephone; three years earlier, the ratio was one in 20 households.

Scott Keeter, a senior researcher at the Pew Research Center, was quoted as saying:

> *It's now about one in four young adults (18–24) who have cell phones only. So far it's not*

> *affecting our results, but it already has the potential to affect studies focused on young people, poor people and renters—groups more likely to have only a cell phone.*

The lack of a landline telephone is one more loss in our arsenal of avenues to reach, locate, or convert a sample member or a householder in a randomly selected address. Plus, cell-phone-only households are symptomatic of a population that is making decisions to filter and control communications with the outside world. The gradual movement away from landline home phones is yet another small but significant chink in our chain of communication. These communication-inhibiters add up.

THE LEARNING CURVE

Front-liners remain optimistic and inventive; they are determined to overcome obstacles. But it has become increasingly evident that the public is on a learning curve. The subjects in the curriculum include the following:

- **Post-9/11 Awareness.** Field interviewers report an increased vigilance on the part of prospective respondents since the terrorist attacks on September 11, 2001.
- **Be Safe from Home Invasions.** Graphic news and print media are causing more householders to respond to unsolicited contacts by ignoring the interruption or yelling a refusal from behind locked doors. Field interviewers are losing the opportunity to establish rapport and sell the study face to face with the respondent.
- **Protect Your Privacy.** People are more alert to the concept of privacy rights—that they have the *right* to decline to answer questions about personal matters.
- **Identity Theft Can Happen to *You*.** The ramifications of identity theft are broadcast on the news and in print media. The public is being trained to question and reject the seekers of personal information.
- **The No-Call List—Sign Up Now.** People are learning to "take charge and take action" to protect against interruptions and solicitations. *We* may know our studies are not sales calls, but some of our respondents lump our activities with all of the other attacks on their time. That's why our interviewers report hearing more often the response, "Take me off your list."
- **Your Time is Money.** A popular movie a few years ago sparked an often-repeated mantra across the country: *Show me the money.* Some interviewers report that more respondents are reluctant to "waste time and money" on activities that are not directly beneficial to *them.* The self-improvement aisle in Barnes and Noble is packed with tomes urging people to maximize their time and effectiveness. One interviewer said to me that a potential respondent stated his hourly rate and did a cost-benefit analysis for her. (The study came up with the short end of *that* stick.) Another interviewer said a respondent was cynical when he

> was assured (in response to the respondent's stated concern) that the study had intrinsic value and nobody was making money off of his answers. The man replied, in essence, "Oh, sure, maybe not you scientists, but I guarantee you, *somebody* will make a profit off of my information at some point in time—probably one of those fat-cat pharmaceutical companies."

Remarkably, response rates remain high (if diminishing) in the survey research field—due no doubt to the professionalism and determination of study designers and field personnel. However, the factors outlined above cannot help but chip away at response rates, especially as the public becomes more practiced in asserting its rights against an avalanche of marketing ploys and attempts to invade or benefit from private information.

FRONT-LINERS SEE SOLUTIONS

How can our research studies avoid being swept off the doorstep by the same stiff broom?

Field interviewers rely on the old stand-bys of survey research to achieve acceptable response rates despite increasing obstacles:

- **Persistence.** Experienced field interviewers learn, like savvy sales professionals, that it's a numbers game—the more "tries," the higher the likelihood of success.
- **Rapport-building.** The first few seconds of contact can make or break the relationship. The interviewer and the respondent may have conflicting needs at the onset—the interviewer needs an interview from the respondent; the respondent may have any number of more dominant needs. The interviewer must immediately discern and communicate some point of commonality of purpose. If he or she is successful, the resistance barrier is softened, and the interviewer will get a chance to choose relevant options from the study's bushel basket of reasons why a respondent should give up his or her time to participate in the study.
- **Intuition.** The "timing" of the message can be a dealmaker or deal breaker. The best interviewers know when to push gently forward and when to retreat. Respondents appreciate an interviewer's sensitivity and respect for their circumstances. Many times, when a respondent says, "It's not a good time," *it isn't.* If an interviewer keeps the rapport and communication flowing as he or she gives the respondent "space" for the moment, the door is more likely to be open for a repeat contact.

Field interviewers are in a unique position to offer real-world solutions from the respondent's point of view. After all, they stand with them on the same doorsteps, braced against subzero wind-chill factors in Chicago or the deadening heat and humidity of an August in Miami.

When pressed for solutions from the study-design perspective, many interviewers take a mental step into the respondents' minds and ask for these considerations:

- Keep it short.
- Keep it simple.
- Make it monetarily worth the time.

In other words, the respondents' needs (as seen from the interviewer's perspective) are contrary to the data and cost realities of health survey research.

While the interviewer may feel we need to "show them the money," there is an undercurrent of concern in our field that the use of monetary incentives has changed our relationship with respondents and may not actually be fostering cooperation in the long run. Another area that merits more study is the seeming growth of complicated studies that demand of our respondents, as one interviewer put it, "everything but their first-born child" (or at least his DNA).

The solution, meanwhile, as we continue to grapple with issues like study complexity and money, may be to more effectively lead respondents to a point of view that is in conflict with their first reaction to our proposition. We need to help them see that the study *is* worth their time in a way that was not immediately evident to them. In other words, we need to get better at leading respondents to a win-win position where our goals and their goals merge for mutual benefit. Perhaps the first step to a better answer to the problem is "more information."

Some interviewers feel their task is getting more and more difficult and the "higher-ups" are not hearing what they are saying. One long-time interviewer said: "There's no doubt it's getting harder out there. I just wish the designers of these studies would come out in the field with me for one full day."

I suggest that professional field interviewers be interviewed themselves in a systematic manner, in conjunction with the approach outlined next.

A BUSINESS-STYLE APPROACH TO A SOLUTION

The business world's overzealous campaign to circumvent the barriers discussed in this paper has exacerbated the problem. Our respondent base is being bombarded with a commercial assault on their privacy and time. Since we are suffering the negative effects of this onslaught (being swept off the doorstep with the same broom), it is worth investigating to see if the solutions in practice by business entities could serve as a stimulus for ideas to solve *our* unique challenges. We are in the data-collection field. Let us collect data! How can we, like the masters of marketing, look at the world through the respondents' eyes and adjust our approach to appeal to *their* concerns and needs?

My suggestion is that survey researchers study the approaches used by industry to uncover ways we can be more effective in

1. Understanding the respondent base's changing worldview.
2. Tailoring our approach, contact scripts, and support materials (like letters, brochures, and fact sheets) to target specifically the wants, needs, and fears of people in our current society.
3. Appealing to a population that has been acclimated to an information environment of sound bites, headline news, and visual-heavy, word-sparse magazine and TV presentations.

The challenges faced by survey researchers are unique and daunting. We are constrained by budget limitations, IRB regulations, and (happily) our commitment to professionalism and ethics. Speaking of ethics, I am not suggesting that we turn into marketers, but I *do* propose that we learn lessons from the people who are in the *business* of gaining cooperation so we can advance our altruistic objectives and benefit society as a whole.

I propose that a study group be formed to

1. Investigate and analyze how successful business marketers are achieving trust and cooperation in a marketplace besieged by the same roadblocks discussed in this paper; and
2. Convert elements of appropriate solutions so we may address more effectively the growing challenges to response rates we are facing in the health survey research field.

I submit that we attack this emerging challenge to response rates *now* as a subject for vigorous study, rather than as a side issue at the launch of each field period.

FEATURE PAPER: Incentives, Falling Response Rates, and the Respondent-Researcher Relationship

Roger Tourangeau, *Joint Program in Survey Methodology, University of Maryland*

INTRODUCTION

Once upon a time, people actually seemed to want to take part in surveys. As recently as 1979, the Survey of Consumer Attitudes (SCA), the University of Michigan's monthly national telephone survey, had a response rate above 70%. Nowadays, the response rate is around 40%, with an average drop of 1.5% per year between 1997 and 2003 (Curtin, Presser, & Singer, 2005). The SCA is a useful bellwether for such trends, because the design has been essentially the same throughout a 30-year period.

In an earlier era, people saw surveys in a more positive light. When many of the oldest survey organizations were founded in the 1930s and 1940s, their founders believed that surveys were an important, perhaps even essential, component of a democratic society and that people would welcome the opportunity to be heard. (For many years, the motto of The Gallup Organization was "Letting people be heard"). In fact, George Gallup, probably the most famous of the early survey researchers, was a celebrity of sorts, with a syndicated column (*America Speaks*) that appeared in hundreds of newspapers. Gallup was even a guest on Edward R. Murrow's *Person-to-Person* television show. Americans don't see surveys or survey researchers in quite the same light anymore.

Several developments have combined to create this sea change in how respondents view surveys and in how researchers view respondents:

- Falling response rates (e.g., Atrostic, Bates, Burt, & Silberstein, 2001; Curtin et al., 2005; deLeeuw & de Heer, 2002; Link, Mokdad, Kulp, & Hyon, 2006) and rising data collection costs as survey organizations increase their levels of effort to counteract the decline in response rates;
- Increased use of incentives in federal and other surveys;
- Increased reliance on "professional" respondents, who join huge Web panels in return for a variety of incentives (ranging from eligibility for sweepstakes to frequent flyer miles);
- The "commodification" of survey data, as organizations demand data but show little or no concern about their quality.

As a result of these trends, the motives of those who take part in surveys have evolved. In the days when people were willing, even eager, to take part in surveys, they did it out of essentially altruistic motives, out of a sense of civic obligation, to help the researchers, or to help their leaders make better decisions. It seems likely that respondents, like the founders of the survey firms, believed in surveys and their value in a democracy. To an increasing extent, respondents have stopped believing in the value of surveys, and they now seem to take part because they expect to be compensated for their time. Apart from any factors involving survey research, the population of the United States has undergone huge changes in the last 70 years. Just to cite two, the population is much more educated (which ought to help response rates) and much more urban (which probably hurts), but my main point is that people today are likely to see the claims of the early survey researchers as idealistic and naïve.

HOW IT WAS

Jean Converse's book on the history of survey research in the United States is good source on how the best-known survey researchers of the 1930s conceived of what they were doing and how they communicated that vision to the public. As Converse (1987, pp. 121–122) notes, "Pollsters [in the 1930s] saw themselves as innovators who would defend a democratic faith with new methods of conveying the popular will."

It's not hard to find evidence supporting Converse's characterization of the early survey researchers. For example, shortly after correctly predicting the outcome of the 1936 election, George Gallup articulated the mission of his work this way: "If democracy is supposed to be based on the will of the people, then somebody should go out and find out what that will is." That quotation is still on The Gallup Organization's Web site. Similarly, Archibald Crossley (who also correctly forecasted the winner of the 1936 election) wrote

> *Scientific polling makes it possible within two or three days at moderate expense for the entire nation to work hand in hand with its legislative representatives on laws which affect our daily lives. Here is the long-sought key to "Government by the people."* (1937, p. 35)

Here is a final quotation, from a few years later, expressing the sentiments of Harry Field, the founder of the National Opinion Research Center:

> *In a democracy, the personal preferences and options of the electorate are a fundamental part of the governmental process....By giving the electorate an opportunity to express itself in the intervals between elections, opinion polls provide a new means of making voters articulate.* (NORC brochure, n.d.; emphasis in the original)

As Converse notes (1987, pp. 308), Field offered to do voter surveys for U.S. senators and members of the House "for no more than the actual out-of-pocket expenses." It's hard to imagine a major survey firm making a similar offer today.

It's clear, then, that the members of the founding generation of survey research saw themselves as contributing in an important way to American democracy and saw survey research as an idealistic (as well as a commercial) enterprise. What is less clear is how the general public evaluated these claims and how they saw surveys more generally. At the very least, people were *interested* in the results of surveys, which were regularly published in newspapers and magazines. For example, apart from Gallup's syndicated column, Roper had a long-standing relationship with *Fortune* magazine, which published survey results. The days of the celebrity pollsters with widely publicized findings on the urgent topics of the day seem long gone; Frank Newport's CNN broadcasts may be the last vestige of this era. Moreover, polls and surveys were (like long-distance telephone calls) an interesting novelty to respondents in those years; the days when surveys were a novelty also seem long over.

HOW IT IS NOW

One of the clearest signs of trouble in the relationship between researchers and the public is the difficulty that the former have getting the latter to cooperate in surveys. Falling response rates may be the greatest single threat survey research has faced in the past 20 years or so. Things were bad in 1999 when a conference was devoted to survey nonresponse (Groves, Dillman, Eltinge, & Little, 2002), and things were even worse last year when *Public Opinion Quarterly* published a special issue on the topic. Groves and Couper (1998) argue that it is generally useful to distinguish among three forms of nonresponse—nonresponse due to noncontact, nonresponse due to the refusal to cooperate, and nonresponse due to inability to participate (e.g., inability to complete an English questionnaire). The decline in response rates seems to reflect trouble on all three fronts.

Take the problem of reaching potential respondents. Caller ID, call blocking, and answering machines have created widespread barriers to getting through to people by telephone (Oldendick & Link, 1999; Tuckel & O'Neill, 1995, 1996). People seem to be eager for these technologies, and they have caught on quickly—the majority of American households now have answering machines, Caller ID, or both, and substantial numbers of households use them to screen out unwanted calls. Many survey professionals report that telephone response rates have fallen over the last decade or so, and at least two major studies provide empirical support to this impression. The first, by Curtin, Presser, and Singer (2005), examines response rates in the SCA from 1979 to 2003. Overall, there has been a decline of about 1% per year in the SCA response rates, and about two-thirds of the decline is explained by increasing rates of noncontact. The second study, by Link, Mokdad, Kulp, and Hyon (2006), examines response rates in the Behavioral Risk Factor Surveillance System (BRFSS) surveys over a period of 42 months surrounding the creation of the National Do Not Call (DNC) Registry in 2003. Looking at data from 47 states (each of which conducted monthly surveys during the period from January 2001 through June 2005), they find on overall downward trend during that period, a trend that wasn't (unfortunately) appreciably altered by the introduction of the DNC Registry. (Link and his colleagues do not attempt to separate out nonresponse due to noncontact from nonresponse due to refusal.)

The other major form of nonresponse is refusal to take part in the survey. Nonresponse due to refusal seems to be rising for household surveys around the world (de Leeuw & de Heer, 2001; Groves & Couper, 1998). Because federal surveys in the U.S. put such a premium on high response rates, they try harder, making more callbacks than they did in the past and taking other measures to maintain response rates. Even in these surveys, though, refusal rates are going up (see, for example, Atrostic et al., 2001), driving up the overall nonresponse rates. Figure 1 shows the overall nonresponse rates and refusal rates for the National Health Interview Survey (NHIS). The increasing overall nonresponse rate mainly reflects a rise in the rate of refusals. Other federal surveys exhibit similar trends.

Inability to complete the survey (because of illness, chronic incapacity, or language problems) traditionally has been a relatively minor source of trouble for general population surveys, but even here the long-term trends are bad. As the percentage of Americans who are foreign-born rises and as the population ages, this source of nonresponse is likely to increase as well. Of course, these demographic changes (unlike the rising noncontact and refusal rates) do not reflect a change of attitudes among potential respondents.

Another sign of the changing relationship between researchers and respondents is the sharply increased cost of data collection; this in turn reflects diminishing returns per contact attempt, increasing use of advance letters (especially in telephone surveys), and wider adoption of incentives in surveys (although, in some cases, incentives save money). In their examination of the BRFSS data, Link and colleagues report that the number of calls per completed case rose significantly in 38 of 47 states with a median annual increase of more than 1.4 calls per complete among those making greater efforts. Similarly, Steeh and her colleagues (Steeh, Kirgis, Cannon, & DeWitt, 2001) examined the trend in the number of attempts needed to reach households in the SCA. The average number of call attempts per interview for the SCA reached 12 in 1999, about double what it was five years earlier.

One response from the survey research industry to the dual problems of lower response rates and higher costs has been to create panels of pre-recruited respondents who are sent e-mail invitations to take part in Web surveys. The panelists are promised a variety of incentives—eligibility for monthly sweepstakes, frequent flyer miles, and so on—in return for completing surveys. A recent review by Baker (2007) mentions nine major Web panels already in operation in the U.S., and The Gallup Organization is creating one as well. In the Netherlands, one paper recently compared 19 Web panels (Vonk, Willems, & van Ossenbruggen, 2006). Relative to other technologies (e.g., telephone surveys), Web data collection is inexpensive. Although a few of the

Web panels are probability samples (e.g., Knowledge Networks), the bulk of them are populated by volunteers (Couper, 2001).

The Web panelists complete a *lot* of surveys. According to Krosnick, Nie, and Rivers (2005), the members of the Survey Sampling Inc. (SSI) panel completed a median of 31 surveys in the past year; the figures were similar for the Greenfield panel, with a median of 27 surveys. The Dutch study indicated that most panel members (more than 60%) belonged to more than one panel; on average, they belonged to 2.7 panels.

Market researchers have begun to explore the consequences for measurement error of this reliance on overburdened panel members. For example, Baker (2007) discusses an emerging typology of undesirable classes of panelists, distinguishing *hyperactives*, *inattentives*, and *fraudulents*. The *hyperactives* join many panels and don't seem to have a clear demographic profile, though as a group, they seem to overrepresent females and the unemployed. *Inattentives* dont work very hard on the surveys they complete, exhibiting such behaviors as straightlining on grid questions (selecting the same answer for every item), very fast completion times, high levels of item nonresponse, and inconsistent or nonsensical answers. The final group of undesirable panelists is the *fraudulents*, who create false identities in order to join panels more than once or lie to meet the eligibility criteria for the panel. This group really wants to be in surveys, though their motives hardly seem altruistic. Of course, there could be considerable overlap among these groups. Baker cites a number of estimates that seem to illustrate the impact of such panelists on survey results. In one survey of businesses, 5% of the respondents reported buying more brands of printers than they bought printers. Taking cognitive shortcuts isnt a new problem in surveys, and it may not be any worse in Web surveys than in other modes of data collection, but the combination of professional respondents in a low accountability medium, like the Web, may spell trouble—a new and more serious kind of trouble—for survey researchers.

HOW DID WE GET HERE?

There are, I believe, three main causes that have converged to produce this impasse. First, people feel busier than they used to, and they have developed a battery of defensive measures for warding off the unwanted intrusions that seem to be a ubiquitous feature of contemporary life. Second, as a number of commentators have pointed out, civic engagement is on the wane; people don't take part in surveys for the same reasons that they don't vote or join volunteer organizations as often as they used to. The idealistic allusions to democracy that figured prominently in the rhetoric of the survey researchers of the 1930s and 1940s have disappeared; in fact, they have a decidedly anachronistic ring. Instead, even the advertising accompanying Census 2000 (in which participation is mandatory) appealed to more self-interest rather than a sense of duty or civic responsibility; Kenneth Prewitt, the Director of the Census Bureau at the time, referred to the approach as "soft greed." Finally, the increasing use of incentives may have undercut whatever altruistic motives respondents once had for taking part in surveys, leaving only economic self-interest in their place.

Time Pressure

One common hypothesis about the cause of the decline in response rates is the overall increase in how busy people are. There has been a steady increase in female labor force participation, one-parent families, two-career couples, etc., over the last few decades. Robinson and Godbey (1999, p. 121) argue that despite these trends, Americans had more free time in 1985 than they did in 1965: free time in 1985 averaged almost 40 hours a week for all people age 18–64; that compares to less than 35 hours in 1965. Despite this, Robinson and Godbey argue that Americans feel tremendous time pressure:

> *Time has become the most precious commodity and the ultimate scarcity for millions of Americans. A 1996* Wall Street Journal *survey found 40 percent of Americans saying that lack of time was a bigger problem for them than lack of money. How did things get so rushed?* (p. 25).

Robinson and Godbey attribute the perceived scarcity of time to four phenomena, which they collectively label time-deepening: (1) we do things faster now than we used to do them; (2) we substitute activities that can be done quickly (such as eating at a fast food restaurant) for activities that take more time (preparing dinner ourselves); (3) we often are doing several things at once; and (4) we undertake more activities on a strict schedule than we used to. Regarding Robinson and Godbey's third point, the extraordinary growth in cellular phones and the widespread adoption of e-mail, text messaging, and instant messaging have created a spectacular growth in opportunities for multitasking, opportunities that many people seem to be seizing. For many white-collar workers, cell phones and e-mail mean that they never really leave work anymore.

One feature of the contemporary experience of being overwhelmingly busy is the frequency of uninvited and unwelcome intrusions from strangers. The intrusions come in an increasing variety of forms—junk mail, telephone solicitations, spam, and other forms of unwelcome e-mail. And among these intruders are survey researchers. According to a series of surveys by Walker Research and the Council for Marketing and Opinion Research, the proportion of respondents reporting that they'd done a survey in the last year went from 19% in 1978 to 82% in 2003 (see Singer & Presser, in press; as these authors point out, the latter figure is undoubtedly inflated by nonresponse, which was much higher in 2003 than in 1978). According to unpublished data by Presser and Kenney (cited in Singer & Presser), OMB approved surveys with twice as many burden hours in 2004 as it did 20 years earlier.

In reaction to the widespread sense of constantly warding off unwelcome interruptions, I suspect that many people have evolved quick-and-dirty tactics, or heuristics, for dealing with them. These heuristics are like spam filters for other media. Three possible examples might be (1) use Caller ID to screen incoming calls and don't answer any from toll-free numbers; (2) route e-mails from unfamiliar sources to a junk mail folder and check them rarely (or never); or (3) throw out all letters and other mail, unless they are clearly bills or are addressed by hand. The point of such heuristics is to deal with intrusions expeditiously, to reduce the time costs they impose, and to avoid the need for acting rudely (e.g., by hanging up on someone). In some cases, the heuristics rely on technology (like Caller ID) or they may be supplanted by automated filters (as with spam filters). Unfortunately, among the uninvited solicitations that may run afoul of these heuristics are requests to participate in surveys. If this conjecture is correct and if many people had already adopted such heuristics before the DNC Registry came on-line, it may explain why it seems to have little impact on telephone survey response rates. People had already made their adjustments to the onslaught of telemarketing calls, and it's too late now to undo the damage.

Civic Engagement & Social Capital

A second explanation for the decline in survey participation involves a long-term decline in civic engagement or social capital. As Abraham, Maitland, and Bianchi (2006) put it:

> *An alternative [to the time pressure hypothesis] is that a person's response propensity reflects strength of social integration or, put differently, strength of attachment to the broader community. People with weaker community ties may be difficult to locate. A person with weak social ties also may be less receptive to completing a survey interview.* (p. 678)

Of course, both increased time pressure and decreased civic engagement could contribute to the decline in response rates. Abraham and her colleagues pit the two hypotheses against each other in analyzing nonresponse to the American Time Use Survey (ATUS). The ATUS sample consists of respondents from the Current Population Survey (CPS); thus, there is a good deal of data available for the ATUS nonrespondents. The major finding of Abraham and her coauthors was that social integration was more important than busyness in explaining nonresponse to the ATUS; low levels of social integration were related to difficulties in contacting ATUS sample members, and noncontact was the major form of nonresponse in that survey.

Two other studies also tend to implicate the importance of civic engagement in nonresponse. One is a well-known study by Groves, Singer, and Corning (2000), which showed that respondents who reported high levels of civic engagement in a previous survey were much more willing to complete a mail survey (without an incentive) than those who had reported low levels. The difference in response rates to the mail survey was substantial 29% (50% for the high civic engagement group versus 21% for the low civic engagement group). When incentives were offered, the difference between the two groups disappeared almost completely. Another bit of evidence on the importance of civic engagement in survey nonresponse was reported by Abraham and her colleagues (Abraham et al., 2006). They note that among those selected for the ATUS sample, those who had previously reported a high level of volunteer activities in a supplement to the CPS were much more likely to complete the ATUS interview than those who had not. This is a very plausible finding; after all, survey participation is often just another form of volunteering to help out other people.[Note]

The costs of incentives. As the Groves, Singer, and Corning study shows, incentives can lure sample members who would otherwise become nonrespondents into completing surveys (and thus potentially reduce the bias due to nonresponse). But the widespread use of incentives to entice respondents (and the increasing use of Web panels consisting of well-practiced, veteran respondents) may introduce new problems. Many studies in the psychological literature have examined what happens when people get paid for doing things that they did once for intrinsic reasons—reasons like civic engagement, interest, simple curiosity. What the evidence shows is that extrinsic rewards (typically, money) tend to dampen intrinsic motivation for engaging in an activity (e.g., see the 1999 meta-analysis of 128 studies by Deci, Koestner, & Ryan). Deci and colleagues examine the effect of tangible rewards that are contingent on engaging in a task or on completing it and find that such rewards have a consistent negative effect on reported interest in the task and how much time people actually spend on it when they are free to choose among several activities. Apparently, one way to kill people's intrinsic interest in doing something is to pay them to do it.

So far, such negative effects of incentives haven't been demonstrated in the survey context. (Singer, 2002, provides a recent review.) But to date, survey incentives typically have been small amounts of money sent ahead of time and not contingent on completing the questionnaire—that is, most surveys offer small prepaid noncontigent incentives. Noncontigent incentives don't seem to have much impact on intrinsic interest, according to Deci and his colleagues. As we move away from such incentives to greater reliance on contingent incentives, generally involving larger amounts of money, the mechanisms involved may change. Instead of triggering a sense of obligation to reciprocate (as small prepaid incentives seem to do), large contingent incentives may encourage respondents to see them (and the opportunity to take part in a survey) in starker, more economic terms—as compensation for their time. And it is this view of incentives that is likely to reduce other motives for doing surveys. The opportunity to be heard has become the opportunity to be paid. The radical satisificing behaviors reported by Vonk and his colleagues and by Baker may be signs of reduced intrinsic motivation, as people come to see themselves as completing a task because they've been promised payment for it.

CONCLUSIONS

Survey response rates are plummeting, and this doubtless reflects a number of broad social trends. People are busier (or at least they *feel* busier), and theyve adopted strategies for fending off unwanted intrusions. Although surveys probably constitute a minor portion of the impositions of contemporary life, the defensive measures people now habitually take serve to filter out survey requests along with other intrusions. Beyond that, it is harder to see surveys in the idealistic light in which the founders of survey research (and presumably the general public) saw them 70 years ago. Civic engagement probably is declining generally, and, in any case, survey participation no longer seems the altruistic gesture it once did. Survey researchers have taken a number of countermeasures to deal with these problems, including boosting the number of callbacks to sample members, greater use of incentives, and increasing reliance on panels of volunteer respondents. The panelists provide a lot of survey data (mostly for market researchers), but it's clear that the data they provide aren't always very good. Results from the psychological literature suggest that using larger contingent incentives may be counterproductive, undercutting intrinsic motivations for doing surveys and leading to extremely low-quality data. Unfortunately, survey data have become a commodity, and, in some settings, its only the amount of data that counts.

REFERENCES

Abraham, K. M., Maitland, A., & Bianchi, S. M. (2006). Nonresponse in the American Time Use Survey: Who is missing from the data and how much does it matter? *Public Opinion Quarterly, 70*, 676–703.

Baker, R. (2007, January). *Separating the wheat from the chaff: Ensuring data quality in Internet samples.* Paper presented at the Institute for Social Research, Ann Arbor, MI.

Converse, J. M. (1987). *Survey research in the United States: Roots and emergence 1890–1960*. Berkeley: University of California Press.

Couper, M. P. (2001). Web surveys: A review of issues and approaches. *Public Opinion Quarterly, 64*, 464–494.

Crossley, A. M. (1937). Straw polls in 1936. *Public Opinion Quarterly, 1*, 24–35.

Curtin, R., Presser, S., & Singer, E. (2005). Changes in telephone survey nonresponse over the past quarter century. *Public Opinion Quarterly, 69,* 87–98.

Deci, E. L., Koestner, R., & Ryan, R. M. (1999). A meta-analytic review of experiments examining the effects of extrinsic rewards on intrinsic motivation. *Psychological Bulletin, 125*, 627–668.

de Leeuw, E., & de Heer, W. (2002). Trends in household survey nonresponse: A longitudinal and international comparison. In R. M. Groves, D. A. Dillman, J. L. Eltinge, & R. J. A. Little (Eds.), *Survey nonresponse* (pp. 41–54). New

York: John Wiley.

Groves, R. M., & Couper, M. P. (1998). *Nonresponse in household surveys*. New York: John Wiley.

Groves, R. M., Couper, M. P., Presser, S., Singer, E., Tourangeau, R., Acosta, G. P., et al. (2006). Experiments in producing nonresponse bias. *Public Opinion Quarterly, 70*, 720–736.

Groves, R. M., Dillman, D. A., Eltinge, J. L., & Little, R. J. A. (Eds.). (2002). *Survey nonresponse.* New York: John Wiley.

Groves, R. M., Presser, S., & Dipko, S. (2004). The role of topic interest in survey participation decisions. *Public Opinion Quarterly, 68*, 2–31.

Groves, R. M., Singer, E., & Corning, A. (2000). Leverage-salience theory of survey participation: Description and an illustration. *Public Opinion Quarterly, 64*, 299–308.

Krosnick, J. A., Nie, N., & Rivers, D. (2005, May). *Web survey methodologies: A comparison of survey accuracy.* Paper presented at the 60th Annual Meeting of the American Association for Public Opinion Research, Miami Beach, FL.

Link, M. W., Mokdad, A. H., Kulp, D., & Hyon, A. (2006). Has the National Do Not Call Registry helped or hurt state-level response rates? A time series analysis. *Public Opinion Quarterly, 70,* 794–809.

Link, M. W., & Oldendick, R. W. (1999). Call screening: Is it really a problem for survey research? *Public Opinion Quarterly, 63*, 577–589.

Oldendick, R. W., & Link, M. W. (1994). The answering machine generation. *Public Opinion Quarterly, 58*, 264–273.

Robinson, J., & Godbey, G. (1999). *Time for life: The surprising ways Americans use their time* (2nd ed.). University Park: Penn State University Press.

Singer, E. (2002). The use of incentives to reduce nonresponse in household surveys. In R. Groves, D. Dillman, J. Eltinge, & R. J. A. Little (Eds.), *Survey nonresponse* (pp. 163–178). New York: John Wiley & Sons.

Singer, E., & Presser, S. (in press). Privacy, confidentiality, and respondent burden as factors in telephone survey nonresponse. In J. M. Lepkowski, N. C. Tucker, J. M. Brick, E. D. de Leeuw, L. Japec, P. J. Lavrakas, M. W. Link, & R. L. Sangster (Eds.), *Advances in telephone survey methodology*. New York: John Wiley.

Steeh, C., Kirgis, N., Cannon, B., & DeWitt, J. (2001). Are they really as bad as they seem? Nonresponse rates at the end of the twentieth century. *Journal of Official Statistics, 17*, 227–247.

Tuckel, P., & O'Neill, H. (1995). A profile of telephone answering machine owners and screeners. In *1995 Proceedings of the Section on Survey Research Methods* (Vol. II, pp. 1157–1162). Alexandria, VA: American Statistical Association.

Tuckel, P., & O'Neill, H. (1996). New technology and nonresponse bias in RDD surveys. In *1996 Proceedings of the Section on Survey Research Methods* (pp. 889–894). Alexandria, VA: American Statistical Association.

Vonk, T., van Ossenbruggen, R., & Willems, P. (2006). The effects of panel recruitment and management on research results: A study across 19 panels. In *Proceedings of ESOMAR World Research Conference, Panel Research 2006* (pp. 79–99). Amsterdam, The Netherlands: ESOMAR.

[NOTE] Another variable that can have a big effect on survey participation is whether the topic is interesting to the respondents (e.g., Groves, Presser, & Dipko, 2004). Since interest in the topic is potentially related to the answers, when interest affects participation decisions, it may create substantial nonresponse bias for the variables related to the survey topic (e.g., Groves et al., 2004; see also Groves et al., 2006).

PANEL DISCUSSION: Reactions to *Incentives, Falling Response Rates, and the Respondent-Researcher Relationship*

Don Dillman, *Washington State University*
Eleanor Singer, *University of Michigan*
Jack Fowler, *University of Massachusetts Boston* and
the Foundation for Informed Medical Decision Making

In lieu of a formal discussant to comment on all of the papers in this conference session, the conference organizers invited three distinguished survey researchers to comment informally on Roger Tourangeau's invited paper, *Incentives, Falling Response Rates, and the Respondent-Researcher Relationship*. Their verbal comments were transcribed and edited slightly for improved readability.

DON DILLMAN:

Well, Roger [Tourangeau] wrote a really nice paper. And, now if I can go on to talk about what I wanted to talk about. *[laughter]*

No, I really, really like that paper. The thesis, as I remember it, is: Respondents are less likely to be found. If you find them, they're more likely to refuse. They also are more likely to not be able to complete the questionnaire, and English language difficulties were mentioned there. And the reasons are they're busier, and there are more time pressures on them, and the contact that people make is unwelcome. It's a good paper.

But, I also wonder if the subtext of the paper comes out kind of like this: We aren't doing very well in getting you to respond to our surveys, and it's all your fault. I think we're getting a little close to blaming the victim. One of the things that I would like to make a few comments on, to maybe be provocative as I suspect that's part of what we're supposed to do….I've tried hard most of my career to start out my day by reading the comic page in the newspaper. And you know it's gotten better and better on a lot of things. I just think people who don't read *For Better or Worse* every day aren't quite living yet. *[laughter]* But anyway, one of my favorites that is no longer there, at least in my paper, is *Pogo*. And the infamous quote from *Pogo* in the newspaper was, "We've met the enemy, and it's us."

I'm just amazed at what we're trying to put people through with our surveys. You know that I don't do much in the health area. So this morning, when I thought about substituting a request for body fluids for questions,…*[laughter]*…this is a long way from the way I remember the 1975 Health Survey Methods conference. I don't think anybody talked about that. But last week someone was asking me for help on a mail survey. I said, "Well, I'll be happy to take a look at it."

And I said, “What are you doing and why are you doing it?” “Well, we used to do it face-to-face, but that’s getting too expensive.” Oh, OK. “And we want to turn it to mail.” “Well, how long is it? ” “Well, it’s 40 pages.”

I’ve tried over the years to find really definitive evidence that responses are declining to mail surveys. With every one of those longitudinal studies that I’ve been able to find, they’re asking for more data later on than they were in the earlier years. I sometimes think that we just keep loading down our surveys with more and more stuff in them. And I’m not surprised that respondents are not happy with us. Not only that, but we move the respondents to the Web, and then we require them to answer every question. So, when we get cutoffs, I don’t think we should be too surprised.

Anyway, back to what this is about. I really hope that the follow-up paper that somebody in here will write is something like this. I think it would make a nice bookend to complement the really terrific job that Roger’s done with why methodologists are no longer capable of getting high response rates. If any of you are inclined, here are some section headings. I liked Roger’s section headings, so I’m going to propose section headings as well about the barriers to response. And I’ll try to move along more quickly here.

The first section is “division of labor.” Recently, at a survey research unit in a large federal agency that I visited, it was me and somebody I’ve known for a lot of years. I wanted to talk to the person about things that were different from the way that it used to be in the agency. Finally, he looked at me and said, “The problem we have in our unit is we don’t understand what each other’s doing.” He said, “We all go to different professional meetings. We’re all emphasizing different parts of the elephant, and I’m not sure we understand each other.” He started talking about the training and background of each of the people in the unit, and how they’re coming out of different disciplines. We’ve had to do that because it’s a more complex world. But somewhere in there, we may be losing sight of the overall part that connects to the respondent. I sometimes wonder as I listen at meetings where I hear the qualitative people and the quantitative people starting to talk, and I just sort of feel like they’re talking past one another and not really coming to grips with some of the issues and how we can get to response. The simple reason is that we’ve gotten big and complex.

Another thing I would propose for the outline would be “organizational compartmentalization.” Every survey takes a lot more approvals than it did in the past, from OMB to IRB to the legal department. Sometimes now we get to the legal department after we’ve been to IRB. And then there are the data analysis people, the processing people, the cost people, the information technology department, and the contractors involved. I want to tell something that happened to me when I was at the Census Bureau in the ‘90s. I’d been there two years, and I commuted across three time zones from Pullman another couple years. And I finally came to the conclusion that I didn’t feel like I was making a whole lot of progress on some things, because I was really hoping we'd get a decennial census in 2000 that was pretty respondent friendly. I didn't think in 1990 it was very respondent friendly at all. The person I talked to about it when I was just about ready to hang it up was Pat Berman, who some of you may remember, and who'd been in the Census Bureau a long, long time. She looked at me and she said, "Well, you have to understand what we are here. We have a division for everything. We have a division for data processing that insists on processing codes that were much bigger than any print on there for the respondent." There were also the envelope people who had to have the envelope decided first because that took longest to order, and it had to be a certain size and shape. And that became the driving force for the way a lot of surveys got printed. She talked about people in the content division that wrote the questions, and insisted that those questions be the way that they wrote them. Sometimes it took a "retirement" in order to get the wording of a particular question changed. Then there was another group that did the questionnaire construction to put it into the exact format. And then there was the field division that took over while others lost control. She said, "We've got a division for everything here except we do not have a division for the respondent." Then she laughed and said, "That's your job, Don."

Well, think about that a little bit. When you start the compromises that are involved now in putting these doggone questionnaires and survey designs together, and how many different divisions there are. Who is it that's in there defending the respondent through all of this? If by chance there is someone defending the respondent it's sort of a secondary objective. So, I thought that was a good observation that Pat made.

Perhaps my best example here of one aspect of organizational compartmentalization happened in 1975 at Arlie House, at the very first Health Survey Methods conference. I was really young in those days. In fact, I think that was the first conference somebody paid me to go to. So I was really excited about getting there. About halfway through the conference, somebody turned to me and said, "Well you appear to be getting good response on mail surveys. How are you getting that response?" And my response to it was, "Oh, well, I'm doing several things on shape of questionnaire and size, and I've got some throwaway questions at the beginning." The room went silent. And the guy behind me—I didn't know what OMB was in those days—literally stepped up from his seat in my direction and said, "You what?" I quickly restated my intent, by saying that I meant to say that I used "interest-getting" questions, which prompted him to relax. However, it was the moderator, Donnie Rothwell from the Census Bureau, who took the tension out of the room. She said, "Well, you know at the Census Bureau in the '40s, we talked about can opener questions to get people started talking. And the can opener we often used in those days was 'How's your family?' And, we would talk a little bit and then we could move in." Donnie also commented about the "scuttle and run" question, which was usually income! You know, one of the things I wonder…sometimes in our surveys, as we get into how much burden is there, and we get approval for the ten questions we can ask or the 100 questions we can ask on it, somehow I think they come from the analyst or the content folks, and nothing's in there for the respondent. That's why I was so fascinated today with Dianne [Rucinski]'s paper, talking about listening to some of the respondents at first. And I wonder if that's something we need to think about. Somehow, in our modern world of data collection we've forgotten about can openers.

"Mode preferences," that's another section. I think is needed for the paper I'm outlining here. We have to start using mail, telephone, and Web for what each of them can do at a time when people are changing how they communicate. Last year I included in a survey some questions about how people were communicating with their closest friends and relatives, how many by telephone, how many by the Internet, and how many face to face. The general public tends to use these modes of communication for different kinds of things. There's a division of labor. There's things that we never talk on the phone about to people anymore, because we do it all on the Internet. I'm not sure that we as surveyors are following very well how people communicate. I want to suggest that that's an important section for this next paper. Roger has a beautiful example [in his paper] that he really cut short [during his presentation].

I was at this conference last fall in Barcelona where designers of web panel surveys were talking. I was really struck by the discussion that was going on there, and a comment made that the respondent as "the enemy." Typologies, were described, e.g. "Well, we have hyperactive respondents, we have inattentive respondents, we have fraudulent respondents, and we also have loyal respondents. And the objective is…can we do something today to figure out who they are and then get them out of our surveys?" Yikes! That concerned me at the moment. I just wondered what would have happened if there'd been a *New York Times* reporter in the room who would have taken that and written an article about how we treat respondents now. Then I went to the web recruitment ads some of the speakers talked about. The bottom line of these ads was, "Come do our surveys. We'll pay you. This is a perfect job for homemakers." And then the next day I got an e-mail from my own university, because I've got a university e-mail address. And it said, "Have us pay your tuition at college and fill out our surveys." So potential web panelists are promised money, and the going rate I think is ten minutes of survey for one Euro in Europe. If there's an enemy here to good surveying, I'm wondering if we've become the enemy, as suggested by Pogo so many years ago. And that really worries me.

The next section for the book, or the paper, is "respondents as clients." Robin [D'Aurizio], I thought that your paper was really nice today in some of the things you were talking [about]. I see all types of businesses treating clients in such different ways and really caring about them. Yesterday I had one of those client experiences when my bag didn't show up at the airport. I talked to the person out front and asked for her supervisor, and she let me talk to the supervisor. As soon as she found out my name and that I was a flyer on the plane, she was just trying to be very helpful to me, even though she was just really not very happy about talking to me. Anyway, I don't think we've thought of respondents as clients yet, and I really think we need to start doing that. One respondent said it nicely to one of our survey staff, I thought. She said, "What part of voluntary is it that you don't understand?" We say voluntary right up front, we put it on the first page, we put it in big letters, and then we call them 20 times. Then I have Dianne's paper, and she says Kish is unfair. That's the first time I've heard that statement, but you know what, I like that. There are some things we need to think about.

Finally, the last section I propose for the paper Roger didn't intend to write, but that I think someone should write is, "use all modes to support the communication process." We've got to start doing that. I think that everybody feels like they have a mode preference. So what they do is say, "I want to use my mode for everything." And "I'm not going to use telephone or Web to support this" or "I'm not going to use mail to support this." We've got to do a lot more thinking about our total communication process and going where the respondents are.

Thank you.

ELEANOR SINGER:

Well, I think that each of us up here is going to say much the same thing in his or her own words. And I'll try to make it short, therefore. Because in addition to everything else, Robin [D'Aurizio] has said just about everything that I think I'm going to say, and has said it better. The trouble is, we were all sort of told to do this, but we didn't really compare notes ahead of time. So, I think we're all going to talk about this a little bit in our own terms.

When I was trying to find a common theme to the papers in this session, except for Roger's, I thought of the word "benefits." I think Mick [Couper] and Dianne [Rucinski] and Koustuv [Dalal] and Robin are all saying in one way or another that people have to see something in it for them in order to participate in a survey. And by something in it for them, I don't mean necessarily an egoistic benefit, but they have to see the thing as somehow being worth their time. So a lot of the people in the survey that Mick was talking about in fact mentioned—in fact as many people mentioned altruistic benefits of participation of those who said they were willing to participate in it as mentioned egoistic benefits like interest in the topic or money. But they have to somehow see the thing as being worth their time. We can reduce their reluctance to participate by reducing risks and harms. But we can't really, I think, persuade them to take part in the survey without somehow convincing them that there's some benefit in it for them. I think Dianne makes this point. The community organizations were willing to go along, but they modified those procedures that weren't seen as beneficial to them. And Koustuv says, you know, these women in India saw the beatings their husband meted out to them as benefits because it guaranteed that they would go to heaven. The survey researcher couldn't offer anything nearly as good. *[laughter]*

There's one exception to this rule. It's one Don [Dillman] and I have some experience with actually. When we were both at the Census Bureau, we did a kind of pretest for the 2000 Census. It was an experiment on what message we should put on the envelopes that people would receive the census forms in. The focus groups we conducted and the organization doing the focus groups kept saying, "Benefits, benefits, you've got to put benefits on the envelope." And we tried three different versions, I think, of benefit statements, and also one that said your participation in this survey is mandatory and noncompliance is punishable by law, or something like that. *[laughter]* Well, that one beat the others by ten percentage points in terms of the return rate. But I think that is the exception that proves the rule because none of us, with the exception of the Census Bureau, [is] doing mandatory surveys.

So, the main point of Roger [Tourangeau]'s paper, I think, is that a shift has taken place in the relationship between the surveyors and respondents so that both of them increasingly come to see this as a "cash nexus" kind of relationship. How accurate is that? And can anything be done about it?

I agree with the description of the falling response rates, and I agree with the points about the use of incentives and the effects that those have, and even about the professional respondents, although I think that's sort of a consequence rather than a cause. But, the point on which I part company with Roger, I think, is on his vision of the golden age where people were high on civic engagement. Because actually we get—by "we," I mean Mick, Fred [Conrad] and Bob [Groves] and I—we get these same responses from the people who say why they would take part in surveys now. They say, "Well, because I like to have my opinion heard, and because you asked me, and because it's going to be useful." The word "useful" came up a lot of times in those open-ended responses. So we know that, on a cross-sectional level, civic engagement and altruistic responses and those good things are correlated with willingness to participate in the survey.

What we really don't have good evidence for is whether there's been a decline in civic engagement over time. In fact, Stanley [Presser] and I tried to find some evidence of that in the recent period where the decline in response rates has been most precipitous, and we really don't find it there. So this, you know, this golden age, I'm not sure. But I think there was a golden age. I just think it had different characteristics.

So what do I think is wrong? First, more and more surveys are being done. Now that's been said, I think, so I'm repeating it. In a way they're easy to do. They're seen as useful for accomplishing a variety of purposes, even though they're not necessarily the best vehicle for doing that. But it's more convenient to do a survey then to get the data some other way. So, why do we ask people about health care expenditures when we know they can't really remember them and they don't want to be bothered to look them up? Why do we do satisfaction surveys and give people 30 seconds or less? Or 10 seconds? They tell us it will only take us 10 seconds. You know, you just have to click this one button. And they do it with self-selected volunteer respondents. Why do they do it, why do we do it, you know, whoever is doing it, when any reasonable person must know that this is not really a good way to measure satisfaction, and doesn't really give them a chance to express what they really think about the situation? My current pet peeve, which I know isn't our fault, but still…Why do we have two-year election campaigns which generate thousands of polls and keep the people we elected a few months ago from doing any useful work?

So I think that the experience of being a survey respondent today is a lot less fun than it used to be. And in a way Robin made my point. When I started doing surveys, which is not quite back in the golden age—not in Roger's golden age, but soon afterward—the interviewers, or the more experienced and better-paid interviewers, had gone to college. Some of them had social work degrees, or they had experience in working with people. They were friendly, they were articulate, and they liked talking to people. They were interested in the surveys that they were doing, just like Robin. I mean, who wouldn't like talking to Robin? I'm so sorry she stopped being an interviewer and went into training. *[laughter]* They saw themselves as collaborators in the research process. I think that's not true as often today, but maybe my golden age is as mythical as Roger's golden age. I don't know.

I do think people are busier, in spite of these surveys that show people having more discretionary time. I think there are more gadgets that encourage us to do more things at once. And I do think—and somebody else said this too, I don't think there's a thing that I'm saying right now that hasn't been said by someone else—there are more gadgets that encourage us to multitask, right? And when you're doing that, I think that does contribute to a feeling of being rushed. You're trying to answer the phone, you're trying to answer the door, you're trying to do something for your kids, and you're talking on the cell phone. It is not conducive to calm and relaxation.

And then the phone rings, and it's an autodialer, and so you're waiting there for whatever it is, seven seconds. Pretty soon you stop waiting for the seven seconds because you know that's an autodialer. It isn't anybody you know and there's no point in waiting or talking to that person. So it isn't just that the interviewer may not be as pleasant. It isn't even an interviewer necessarily, right? It's somebody's recorded voice. What fun is that? So, then, either in response to this or for other reasons cited by Groves and Couper, the response rates started to decline.

So what did we then in desperation do? We started paying respondents, and we started paying bonuses to interviewers. And then I think the trouble really began. In the paper, Roger said we haven't shown this yet, that paying really produces a decline. But I think we know that interviewers' expectations affect their response rates. We also know that interviewers like incentives. And that they feel more comfortable in approaching respondents when incentives are being used. I suspect that interviewers get higher response rates when incentives are used. Or, at any rate, I think they get lower response rates when incentives are not used. So I think it's kind of a vicious cycle. I don't know if it leads to higher incentives, which is Roger's hypothesis. But it may very well.

So, what can we do? Well, here's where we really say the same thing. Concentrate on making the experience more rewarding to the respondent. Give respondents good reasons for why they should spend their time this way. Now I understand you have to get them to talk to you in the first place. I'll come to it. Second, strip from the survey those questions that are unreasonably burdensome for respondents and figure out some other way to collect the data. Or else pay the respondents a fair rate for collecting data, for collecting accurate data, and transmitting them to the interviewer or the survey organization. Consider asking some of these questions of sub-samples, and imputing the data for the rest. Third, hire better interviewers, pay them more, and make interviewing a profession. I think we would benefit from the professionalization of survey interviewing. Fourth, personalize initial contacts with respondents. I mean we've known this for a long time. Everything I'm saying is going to cost more money. I know that. But you know you're going to spend it one way or the other. *[laughter]* I'm suggesting that we try spending it this way. Use mail. Use first class postage. Leave messages on answering machines by people who sound like they would be fun to talk to and who are interested in the topic of the survey. Eliminate autodialers. It's more effective in the long run I think. Diversify the data collection methods that the survey organization offers, and suggest alternative ways of collecting data to the client if the job doesn't require a survey, if it can be done some other way. If you can get the data some other way, good data, or even better data, some other way, then let's try to do it without using the survey. So that's how you increase the rewards.

I've got three more points to make. This is how you increase the rewards. Now, how do you reduce the costs? Follow Don's and Mick's advice. Make the experience user friendly. Use pleasant, smart interviewers. Design the questionnaires. Design user-friendly computer interfaces and easy-to-read and -answer mail questionnaires. Keep the burden of responding low in other ways. Don't ask any more intrusive questions than you have to, and justify the ones you ask to yourself and then to the respondent. Make surveys anonymous when possible. I know we all want to collect longitudinal data and keep the surveys going forever. Ensure respondents of confidentiality when anonymity is not possible. Be honest about how much protection you can offer them, especially if the data you collect are sensitive.

All right, I could go on. But I will conclude with my favorite quotation. I wish I had the cartoon but I don't have it with me. It's by Jules Feiffer, who has the interviewer knocking on one door after another, and everyone turns him down. He gets to the last door and turns away in disgust, and says, “OK, I’ll just go back to making it up.” *[laughter]*

JACK FOWLER:

There is some commonality in our thoughts. I like the paper a lot that Roger [Tourangeau] wrote, and there are a lot of things I agree with. The one point I don’t agree with is that people are less willing to do surveys than they used to be.

Recently we drew a sample of Medicare patients who’d had prostate surgery two or three years prior, so it was a national survey. We mailed them a questionnaire, mailed them a reminder card, and then we called up the people that didn’t respond and interviewed them on the phone. We got responses from about 90% of selected patients. And at least half of the ten percent we didn’t get were for reasons other than refusals: we couldn’t get them on the phone or, in some cases, they were too ill to respond or did not speak English. Refusals were about as close to zero as you could get. I think the reason cooperation was so good was that potential respondents could readily see the point. We said, “Look, the reason we’re doing this is that you went through an experience. You had an operation. A lot of other guys are going to have the same operation, and we want good data about what happened to you so we can feed it back to others. Getting doctors and patients to know what happened to you will be really helpful.” So the purpose was pretty easy to understand. How answering the questions will make a difference and how they could contribute were pretty easy to understand. The purpose of the survey was clearly relevant to their lives. And reaching them was not much of a problem. The mail addresses were really good. The phone numbers were somewhat less good (because Medicare does not collect those and we had to rely on reverse directory services).

Just to show that willing respondents are not restricted to prostate cancer patients talking about their own care, Trish Gallagher recently published a paper about a survey of people enrolled in Medicaid in Massachusetts. The CAHPS survey gives people the opportunity to report on their experiences with receiving health care. In that survey, we did a mail survey first. A lot of people didn’t respond, but I think we got maybe 40%. Then we made phone calls got another 10% or 15%. Then we went out in person and ended up getting responses from 75% of selected beneficiaries. Of the balance, for 10%, the contact information was not good at all. There was no possibility of finding them. So we got 75% out of 90%, and a few of those people couldn’t speak either of the languages—English or Spanish—the survey was offered in. The key point is that refusals among this Medicaid population were really pretty trivial—no more than 10%.

Again, I think an important feature of the survey is that it is easy to understand why the survey is being done and how the goals are relevant. “We want to know what your experience is with Medicaid and getting health care.” It’s not a huge stretch to understand why that might make sense.

Another very important feature of that survey is that we gave potential respondents three different modes in which to respond. There were identifiable subsets of the population that used the different modes (to echo some of the points that Don was making). So the strength of that design was that we offered three modes, so we were usually able to find a mode that would fit somebody's style, and by which we could get at them. Also, in some cases, the reason a mode was successful was that it enabled the case for participating to be effectively presented. I think when we can find a way to effectively present what the survey's about, and if there is a reasonable case to be made for why answering the questions can make a contribution to something that matters to respondents, large percentages of people will participate.

I think the problem that we're hearing the most with respect to survey nonresponse is the difficulty in finding a way to effectively present the case for the survey. The telephone seems to be the biggest culprit. There are undeniable problems in the reliance that we've had on the telephone as a main way of getting population- based data. Gated communities, high-rise apartments with security, and all those things that are barriers to in-person interviews exist, too, and they certainly make for contact problems. However, I think people are willing to be helpful if we can find ways to get to them.

I'm going to talk about two other issues. First, the use of incentives. One of the roles of incentives in our current world, I think, is to get people's attention, to get them to read what it is you wrote or listen for a little bit to what the interviewer has to say before hanging up. Ten dollars has a big effect on the likelihood that a doctor will return a mail survey. I don't think it's because we buy his or her time or good will. Rather, I think the ten dollars makes it harder for the secretary to throw the questionnaire away and probably greatly increases the odds that the doctor reads the cover letter. I don't think doctors will fill out a survey if it appears poorly designed or it doesn't relate to issues they value. But I think if you actually have a reasonable research problem that relates to their interests, and you can get them to read the cover letter, a lot of them will respond.

And this comment I will make on Eleanor [Singer]'s comments about incentives and interviewers: I've been part of two experimental studies of interviewers and incentives. In randomized designs, interviewers gave half of their respondents money and the other half received no monetary incentive. In both studies, they got better response rates when they used the money. So in a follow-up to the experiments, interviewers always offered an incentive in the expectation that their response rates would mirror the results from the experiment. In both cases, lo and behold, the response rates went back down to the level of non-incentive rate.

I'm convinced that what happens is that interviewers get to rely on incentives as the reason for enlisting cooperation, and money alone is not a good way to enlist cooperation. I think most people cooperate with a survey because it's something they think is worth doing for its own sake. Adding incentives to the intrinsic motives for cooperating can improve response rates. However, for most surveys, I think the key to a good response rate is to make sure interviewers effectively present the intrinsic reasons why somebody would want to do help with the survey.

Forty years ago, Charlie Cannell and I interviewed people who'd been National Health Interview Survey respondents. The questions looked a lot like yours, Eleanor: "Why did you do the interview?" and "Why might you not want to do it?" Your findings nearly replicated ours: Confidentiality was hardly on people's radar screen. Sometimes they weren't sure they wanted to answer the kinds of questions that were being asked. The main reason that they said they agreed to the interview was because they thought they could be helpful, and that it would be a useful thing to do, even though, on average, they were woefully uninformed about how participating in the health survey would actually be helpful.

The other factor in respondents' decisions to be respondents was, of course, the interviewer. We have all kinds of data that show that interviewers are really decisive in enlisting cooperation.

So, as I said this repeats a lot of what other folks have said. I do think that looking for the best strategy to get at people—a strategy that provides the best chance to present the case for why this survey is useful—is our most important challenge. I think people are willing to help with research if they can come to understand that it is an effective way to help with a problem they care about. To kind of turn Don's points around, I think what we have to do is be less caught up in our favorite strategies, the commitments to protocols that we make for reasons that have nothing to do with collecting the data or coming to terms with respondents' own needs, and think more carefully about how we can most effectively make the case to would-be respondents that being a respondent is a good thing to do.

Thank you.

SESSION 4 SUMMARY

Lisa Schwartz, *Mathematica*, and Cheryl Wiese, *Group Health Center for Health Studies*

Relationships between researchers and participants are short-term and are becoming increasingly complex. The goal of this session was to offer solutions to improve researcher-participant interactions. The following summary highlights the lively discussion and valuable advice in response to the session presentations.

NEED FOR RESPONDENT-CENTERED SURVEY DESIGN

We need to focus our attention on reducing **respondent burden**. Despite what all of our research has told us in the past, we increase the burden on respondents when we continue to lengthen questionnaires, ask for biomeasures, increase the frequency of appeals for survey participation, and rely on surveys when the information we seek may be more appropriately gathered using another information-gathering tool. Further, we ask respondents questions that they either cannot answer accurately (e.g., health expenditures) or cannot answer completely (e.g., satisfaction with services).

We must **emphasize the benefits** of participation in at least as balanced an approach as we present risks. Individual-level benefits include the importance or salience of the topic to the respondent and incentives. For benefits that are altruistic in nature, we must appeal to people's desire to be helpful and emphasize the societal benefits of participation. A series of experiments by Couper and colleagues (as they described in this session) demonstrated that topic sensitivity is more of a concern than disclosure risks on willingness to participate, and qualitative data suggests that the benefits of participating can compel cooperation.

Personalized appeals; professional, engaged interviewers; and multimode surveys may promote a more respondent-centered approach. We need to make the case to sample members—this is why it's important that you participate; this is why it will be useful or beneficial to you. Once we've made the case, we then need to limit what we are asking respondents to do to something reasonable.

Community-based participatory research may be one approach that gives the respondent more of a voice in all aspects of the study. IRBs and universities may not be fully supportive of community-based participatory research, and researchers themselves may be reluctant to pursue this type of research because it requires compromises that we are trained to avoid. Community-based participatory research requires adaptive methodologies that can be refined through an iterative process.

CHANGES IN THE PRACTICE OF SURVEY DESIGN THAT MAY HARM SURVEY RESPONSE

As surveys become more complex, they require greater specialization of skills in order to design, implement, manage, and analyze survey data. In response to the need for Web designers, voice technology experts, focus groups, cognitive interviewing, etc., survey firms have become increasingly compartmentalized with different divisions hiring people with very different backgrounds and skill sets. It becomes more difficult for each division to understand, effectively communicate with, and complement what the other divisions or departments are doing.

In the past, many people who became survey researchers started as interviewers. As survey research has become "professionalized," this has changed. We need to find ways to keep interviewers at the study design table, as they are the experts on survey administration and are the best representatives of the respondent's perspective. Researchers should commit themselves to regularly reading an introductory script and survey out loud, conduct interviews themselves, serve as respondents during the testing or pilot phases of studies, and be active in the testing and administration process to study the interviewer-respondent interaction.

The switch from token **incentives** to substantial incentives may contribute to the commoditization of data whereby people participate not necessarily "to be heard" but to be paid. The use of incentives also can diminish intrinsic motivations for participating. There has been increased emphasis on self-serving reasons for survey participation (interest in the topic, interest in being paid), but respondents still want to participate for altruistic reasons as well. We need to make clear the personal benefits of participating while also appealing to people's desire to be helpful. We must continue to focus our efforts on training interviewers to make the most of their initial interactions with respondents by appealing to the myriad intrinsic motivators that encourage survey participation. Learning to appeal to altruistic motivators may help reduce our reliance a monetary incentives, a reliance that can hamper interviewers' effectiveness when they are working on studies that offer smaller or no incentives at all. For disaster-related research, we may want to consider ways to help meet basic needs of respondents or give back to the communities as a different form of incentive, such as offering to donate time to help rebuild the homes and communities of the respondents from whom we are seeking information and time.

IRBs can offer challenges to respondent-centered survey design. The emphasis on disclosure of potential risks means that our appeals to sample members may overemphasize risks and risk protection, neither of which appears to significantly affect willingness to participate, and underemphasize societal and personal benefits of participating, which do seem to have positive effect on willingness to participate. The IRB requirement that we note under what legal authority we are conducting the research is also at odds with factors that influence participation. But the goal of writing materials that can be understood at an 8th-grade reading level is one that we health researchers should tackle in our efforts to appeal to both the intrinsic and altruistic motivations of potential respondents. Research shows that even more educated patients and participants prefer their health information be presented at an easier reading level (Davis et al., 1996). Indeed, efforts have been made on this front by health researchers, including the Readability Toolkit (Ridpath, 2006), a straightforward approach to creating and revising written health research materials to the 8th-grade level of reading comprehension.

INTERVIEWER EFFECTS & THE RESPONDENT-INTERVIEWER INTERACTION

In keeping with the theme of emphasizing the benefits of participation, we need to do a better job of understanding survey participation from the perspective of respondents. Inter-viewers need to be trained in active listening techniques to help them understand the situation of the people to whom they are talking and find a way to offer them something of value. Community-based organizations and experienced interviewers may recognize and implement these techniques already by making personal appeals to potential study participants or organization members.

FUTURE RESEARCH

> *The concept of quality, and indeed the concept of error, can only be defined satisfactorily in the same context as that in which the work is conducted. To the extent that the context varies, and the objectives vary, the meaning of error will also vary. I propose that as a definition of error we adopt the following: work purporting to do what it does not do. Rather than specify an arbitrary (pseudo-objective) criterion, this redefines the problem in terms of the aims and frame of reference of the researcher. It immediately removes the need to consider true value concepts in any absolute sense, and forces a consideration of the needs for which the data are being collected. Broadly speaking, every survey operation has an objective, an outcome, and a description of that outcome. Errors (quality failures) will be found in the mismatches among these elements.*
> (O'Muircheartaigh, 1997, p. 1)

NONRESPONSE BIAS & DATA QUALITY

We have a tendency to focus on declines in response rates and historically have relied on response rates as our data quality indicator, but we really need to focus some attention on nonresponse bias and other measures of quality.

Do we recognize that the value of survey research is relative to the client's needs, or is there a gold standard that has to do with the rigor with which the information was collected? We need to consider "fitness for use." While it is true that a precise estimate that comes too late is not particularly helpful, it's also true that we can collect high-quality data quickly. For example, the Current Population Survey puts out high-quality employment estimates on a monthly basis. Clients need to understand the compromises they are making so they can make an informed decision about whether they can use a less precise estimate to answer their research questions. If all we can provide is an imprecise estimate, we need to question whether the survey is really necessary or the best vehicle for obtaining the information that the client needs. Even when clients decide they want a survey done and can live with imprecision, we need to be concerned about the quality of the information we provide. If we provide a quick but not-that-accurate estimate, even with all the necessary caveats, we cannot be sure how the client is going to use the data, raising concerns about the misuse of imprecise estimates in particular.

PROFESSIONAL INTERVIEWERS

For the past 30 years or so, people have been calling for better pay and work environments for interviewers, making survey interviewing a profession rather than a part-time job. There are some market tensions here, as some firms will pay interviewers less, won't offer benefits, and then will be able to win contracts because they are most cost-competitive. We need to document that there is a relationship between interviewer professionalism and data quality.

WEB SURVEYS

Web surveys cannot substitute for respondent-centered and interviewer-facilitated interviews. We are finding increasing opportunities to use Web surveys when people are going online for other reasons—for example, Web portals that provide health information to respondents or provide an intervention are good opportunities for also gathering survey data. Web surveys may be especially appropriate when "cheap and fast" are needed, such as when we are doing disaster response, but we need to understand how good or bad the data may be. The Web is an additional tool but not a replacement for other forms of data collection.

INCENTIVES

The increased used of monetary incentives that go beyond "tokens of appreciation" to payment for survey participation contributes to the commoditization of data and may reduce people's intrinsic motivation to participate in surveys. The use of incentives may boost response rates to individual surveys in the short run but may be contributing to overall declining response rates in the long run.

We need additional research on the use of incentives. Leverage salience theory suggests that monetary or other incentives might best be used to increase the representativeness of the study sample by drawing people who would not participate otherwise. We need to do further research in this area and look at the longer-term impacts of incentives on participation.

Additional research is needed on the use of nonmonetary incentives in health survey research. How do we make health survey participation *itself* valuable to respondents?

MULTIMODE AS TOOL FOR RESPONDENT-CENTERED DESIGN

Offering surveys in multiple modes may be one way to promote respondent-centered design. To take advantage of multimode capabilities, we need to do additional research to understand the relationship between respondent characteristics and mode preferences. To date, the preference data suggests that people may simply be stating a preference for the mode that would make it easier to *not* respond (e.g., preferring the Web to interviewer-administered modes). However, there is little research that looks at mode preference and mode adoption or completion or that would allow us to offer specific modes based on known respondent characteristics.

REFERENCES

Davis, T. C., Bocchini, J. A., Jr., Fredrickson, D., Arnold, C., Mayeaux, E. J., Murphy, P. W., et al. (1996). Parent comprehension of polio vaccine information pamphlets. *Pediatrics, 97,* 804–810.

O'Muircheartaigh, C. (1997). Measurement error in surveys: A historical perspective. In L. E. Lyberg, P. Biemer, M. Collins, E. D. de Leeuw, C. Dippo, N. Schwartz, & D. Trewin (Eds.), *Survey measurement and process quality* (pp. 1–28). New York: John Wiley & Sons.

Ridpath, J. (2006). *Center for Health Studies Readability toolkit* (2nd ed.). Seattle: Group Health Center for Health Studies.

INTRODUCTION TO SESSION 5: Trade-offs in Health Survey Design

Brad Edwards, *Westat*

Total survey design and total survey error operate in a "total survey cost" environment, but the relationship between design and cost is poorly understood and often ignored. In today's climate of declining response rates and severe cost constraints, it is difficult to articulate the relationship but imperative to make it explicit. This session examines trade-offs between design and costs.

From Wikipedia, "a trade-off usually refers to losing one quality or aspect of something in return for gaining another. It implies a decision to be made with *full comprehension* of both the upside and downside of a particular choice" (emphasis added). A nearly universal trade-off in the business world is time, money, and quality. Conventional wisdom says that only two of these can be maximized in any given application at the same time. Engineering abounds with trade-offs. It is rare for a bridge or a building to be functional, beautiful, built on time, and built within budget.

In health survey design, we seldom are very concerned about aesthetics, but we worry a lot about timeliness, cost, and quality. Methodologists and managers have more design options today (e.g., CAPI, ACASI, Web) than when the first Health Survey Research Methods Conference was held more than 30 years ago, but they must address much higher survey costs. Declines in response rates have been well documented for telephone and in-person modes since the early 1990s (Atrostic, Bates, Burt, & Silberstein, 2001; Curtin, Presser, & Singer, 2000), while demands for increased quality have grown more insistent. We seldom fully grasp the implications of our trade-off decisions. A major challenge for today's health surveys is to make the relationship of design to quality, cost, and timeliness more transparent.

The theoretical framework for this session is drawn from total survey design and total survey error. It offers examples of trade-offs in a number of applications, including responsive design using paradata, design molded by survey goals and parameters, a simulation model for quantifying error, and adaptive design in a panel survey. The final paper addresses mode choices in the context of data quality and cost. We hope this can be a starting point for research on health survey design trade-off decisions.

REFERENCES

Atrostic, B. K., Bates, N., Burt, G., & Silberstein, A. (2001). Nonresponse in U.S. government household surveys: Consistent measures, recent trends, and new insights. *Journal of Official Statistics, 17,* 209–226.

Curtin, R., Presser, S., & Singer, E. (2000). The effects of response rate changes on the index of consumer sentiment. *Public*

Opinion Quarterly, *64*, 413–428.

Wikipedia. (n.d.). *Trade-off*. Retrieved July 24, 2007, from http://en.wikipedia.org/wiki/Trade_off

FEATURE PAPER: Responsive Design in a Continuous Survey: Designing for the Trade-off of Standard Errors, Response Rates, and Costs

Robert M. Groves and James M. Lepkowski, *University of Michigan*
William Mosher, *National Center for Health Statistics*
James Wagner and Nicole Kirgis, *University of Michigan*

INTRODUCTION

Two phenomena are the current focus of attention of much of health survey research at the time of this paper—falling response rates among self-report surveys of persons and rising survey costs for probability sample surveys that have aspirations of high response rates. This is a paper motivated by both of these phenomena.

The literature on survey costs is rather limited. All the traditional survey sampling texts (Cochran, 1977; Kish, 1965; Särndal, Wretman, & Swensson, 2003) motivate the attention to costs in optimal sample design discussions. There they note that to minimize sampling variance per unit cost, a cost model reflecting the key design features of the sample (e.g., stratification and clustering) is required. Little of the discussion in these books and the related literature describes the problems of specification of the cost model and the estimation of key parameters in the cost model.

There is one monograph-length treatment of survey costs written in 1967, now out of print, by Sudman—*Reducing the Costs of Surveys*. It presents interesting empirical data mainly from face-to-face interviewing at the National Opinion Research Center. The data contain breakdowns of the hours of interviewers on a survey, separating the effort into different functions of the interviewer job. The text *Survey Errors and Survey Costs* (Groves, 1989) presents some commentary on survey cost modeling. One single conclusion out of all the literature is the mismatch between the cost categories used in most survey budgets (e.g., total number of interviewer hours, total number of supervisory hours, total travel costs), on one hand, and the needs for cost categories that are useful to design decisions (e.g., the cost of traveling from home to a sample segment vs. the cost of traveling within a segment, the costs of a callback to a case vs. the cost of the first call to a case, the cost of a noncontact call vs. the cost of a contact call). That is, every day during a survey data collection period, interviewers and survey managers are making decisions that affect the composition of the costs of the survey.

Costs and response rates are features that seem to be tightly linked in most survey modes. Repeated efforts to contact and gain the cooperation of sample units cost money. The evidence that response rates are falling is plentiful (de Leeuw & de Heer, 2002). The most common reaction to this phenomenon in scientific and government surveys is to increase efforts to retain response rates. The efforts merely increase cost. Controlling costs and maximizing response rates is not simple.

The purpose of this paper is (a) to review the application of responsive design concepts to the use of paradata in a continuous survey, (b) to illustrate various midcourse decisions based on paradata, and (c) motivated by them, to examine the problem of forecasting numbers of survey interviews. This paper contains few evaluations of these steps; its purpose is more to generate discussion and debate for improvement of the aims of responsive design.

RESPONSIVE DESIGN IN A CONTINUOUS SURVEY SETTING

Responsive designs (Groves & Heeringa, 2006) are designs that use paradata-based indicators of costs and quality to intervene in the survey design during data collection. Some of these interventions are based on all cases (changes of calling patterns); others, on probability subsamples of cases (two-phase samples of nonrespondents).

Responsive designs are organized about *design phases*. A design phase is a period of data collection during which the same set of sampling frame, mode of data collection, sample design, recruitment protocols, and measurement conditions are extant. When different design phases are conducted on independent samples (e.g., distinct treatments of sample replicates with known probabilities of selection to each treatment), they offer measurable contrasts of phases, using traditional statistical estimators. Sometimes phases are conducted simultaneously—for example, when there is a randomized set of question modules assigned to sample replicates. However, sometimes phases are conducted sequentially in a survey design (we use such an empirical example below) and apply to subsets of the sample respondents that are neither independent nor random samples (e.g., special incentives and procedures for final nonresponse follow-up). In such cases, the phase inclusion probabilities for sample elements must be modeled in a fashion similar to the response propensity models that are commonly used in addressing survey nonresponse (Little & Rubin, 2002). Note that this use of "phase" includes more design features than merely the sample design, common to the term "multiphase sampling" (Neyman, 1938).

A valuable tool in implementing responsive designs is a set of *leading indicators* of error sensitivity. A leading indicator of error sensitivity is a statistic whose estimate is maximally sensitive to phase maturation. For example, Groves, Wissoker, Greene, McNeeley, and Montemarano (2001) suggest using a statistic to measure the maximum level of noncontact error among all statistics in a survey. They examine the percentage of households occupied by one person who is employed outside the home and lives in a unit subject to some sort of access impediment (answering machine, locked entrance). They demonstrate empirically that the design feature of number of maximum calls in a callback rule is a better predictor of the expected value of this statistic than any other statistic in the survey. Thus, this statistic would be a candidate for a leading indicator of noncontact error for the survey.

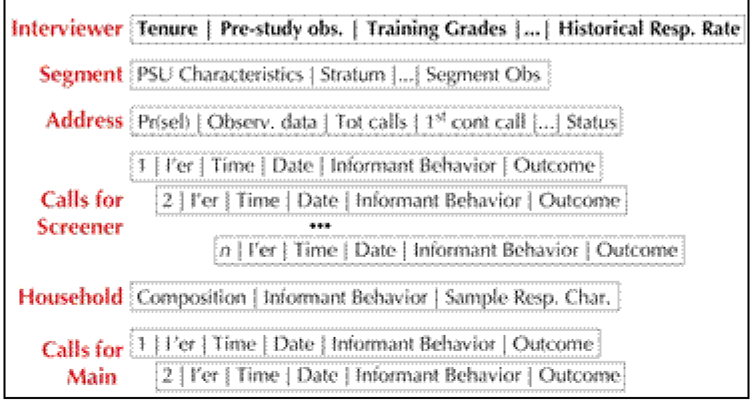
The value of combining responsive design concepts and continuous interviewing is that continuous interviewing provides ongoing enrichment of paradata over repeated cycles of the interviewing. This permits continuous improvement of processes to be implemented.

To illustrate our ideas, we will present empirical data from the National Survey of Family Growth (NSFG), which uses a cross-section area probability sample on four quarterly replicate samples in approximately 33 primary areas each year. Each quarterly sample contains approximately 5,000 addresses. Each year, a new set of non-self-representing sample areas are rotated into the sample and the prior set rotated out. Field operations are continuous. A screener interview is requested at each sample household; a household containing one or more persons 15–44 years old yields a sample person. A "main" interview lasting between 60–80 minutes is requested of the sample person.

Using survey paradata, various precursors of cost inflation of completed interviews can be tracked during the survey period. The NSFG has created a paradata structure that facilitates such monitoring. Figure 1 is a graphical display of that data structure, containing information on interviewers (from a self-completed form), sample segments (from observations of listers), sample housing units, calls, contacts, and sample persons (all from interviewer observations).

Each evening, all interviewers telecommunicate their day's work back to the central office, permitting daily monitoring of some of the key paradata indicators. The indicators are measures of interviewer effort, relative difficulty of the current active cases, and the product of the interviewer's effort (in terms of case statuses).

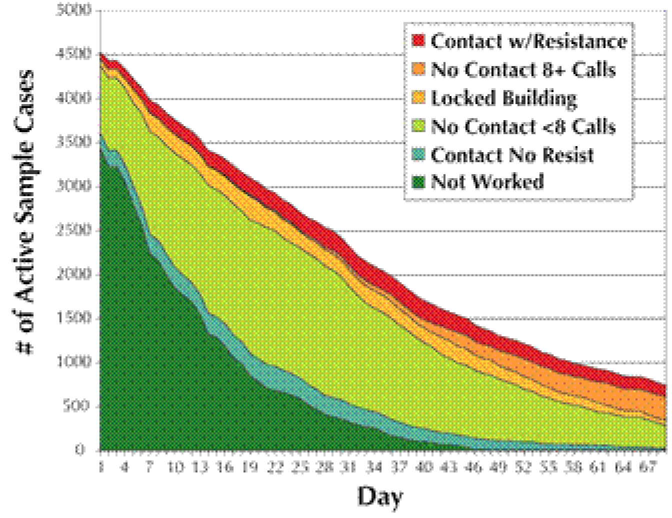
Figure 1. Record Structure of NSFG Paradata


Interviewer
Tenure | Pre-study obs. | Training Grades | ... | Historical Resp. Rate
Segment
PSU Characteristics | Stratum | ... | Segment Obs
Address
Pr(sel) | Observ. data | Tot calls | 1st cont call | ... | Status
Calls for Screener
1 | I'er | Time | Date | Informant Behavior | Outcome
2 | I'er | Time | Date | Informant Behavior | Outcome
***
n | I'er | Time | Date | Informant Behavior | Outcome
Household
Composition | Informant Behavior | Sample Resp. Char.
Calls for Main
1 | I'er | Time | Date | Informant Behavior | Outcome
2 | I'er | Time | Date | Informant Behavior | Outcome

THE APPLICATION OF THE NOTION OF "PHASES"

One simple cost model of survey data production at the highest level of aggregation notes that a survey starts with a set of raw materials (i.e., sample cases), applies various efforts to them (e.g., advance letters, calls on units, contacts with household members), and produce products (i.e., data records). In contrast to

Figure 2. Size of Active Case Sample, by Day of Data Collection Period



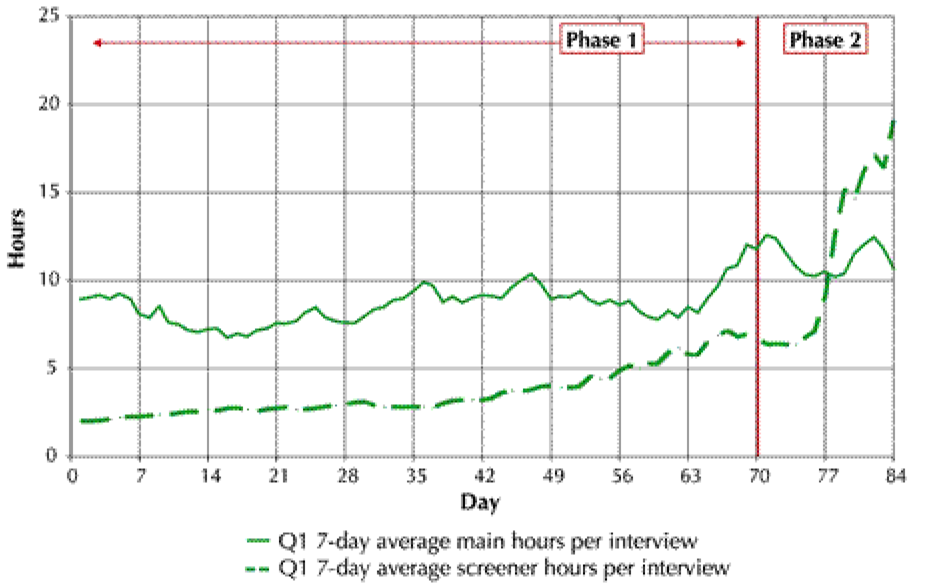
many production processes, the materials are fixed at the inception of the project and not supplemented with other materials (note: we ignore the designs that release new sample cases into the data collection activities throughout the survey period). On the first day of the survey period, all cases are "untouched"—they have received no calls on them. On the last day of the survey period, there are few or no cases that have received no call attempts; there are many fewer active cases, and many of the active cases have revealed low propensities to be interviewed.

Figure 2 presents a graphical display of the area probability sample of housing units in a face-to-face survey that involves screening based on a household listing to sample parsons 15–44 years of age. The *y*-axis of the graph is the number of active sample cases; the *x*-axis is the day of the 70-day survey period. On the first day of the survey period, there are roughly 4,500 active cases. On the last day of the survey period, there are less than 1,000. The darkest bottom portion of the graph represents those cases that have not received any call attempts. The groups of successively higher positions on the stacked graph are ones with lower propensity to yield interviews, based on prior experience (e.g., cases contacted but showing some resistance to the screener interview request). Thus, the graph makes it clear that, as the survey period progresses, the number of cases to work in the sample declines, and the composition of those remaining cases is less benign to the survey request.

The fact that the "raw materials" of the production process deteriorate in their qualities over the course of the survey period implies that the effort required per completed data record also may increase. Every hour of effort of the interviewers is likely to produce fewer interviews at the end of the survey period than at the beginning of the survey period. This observation leads to a common concern of survey managers that the last portion of a survey data collection can be productive of rather great cost inefficiencies. It's also easy to speculate that the longer the survey period lasts or, alternatively, the larger the effort expended, conditional on a sample, the higher the total survey costs.

For example, some organizations use a simple ratio—the number of

Figure 3. Seven-Day Moving Average Number of Interviewer Hours Worked Divided by Main & Screener Interviews, by Day of Survey Period



interviewer hours worked to the number of interviews produced—as a measure of efficiency of the data collection. Figure 3 illustrates one common phenomenon. The graph plots two ratios—the ratio of total interviewer hours to number of main and number of screener interviews produced. The top line is the hours per interview for the main interview, varying from about 8–10 hours per interview. The bottom dashed line is the hours per screener interview, ranging from 2–3 to about 6 hours. (Note that the numerator of the two ratios is the same for each day.) The vertical line at day 70 is the dividing point for two phases of the survey, the second using a subsample of active cases unresolved in the first phase. Note how the number of hours required to produce a screener interview consistently increases over the days of the survey period, reflecting the steady erosion of the likelihood of contact and cooperation of the active case base shown in Figure 2. The ratio for the main interview shows a different pattern for several reasons. Main interviews are granted by the respondent him- or herself, who may not have been the informant at the screening interview. Further, interviewer attention is shifted from screener to main interviews during the course of the survey period. And as the survey period progresses, there is a higher proportion of main interview calling to highly reluctant respondents.

One feature of Figure 3 is a large focus of survey managers—notice the sharp inflation of hours per main interview in the last week of phase 1 (days 63–70). During this time, interviewers are increasingly calling on cases that have revealed their low propensity to be contacted or to cooperate.

We take rapid cost inflation of each product as *prima facie* evidence that phase capacity has been reached. When phase capacity has been reached, it is attractive to stop the phase and begin another phase. The design of the second phase should be such that those cases not successfully measured in the first phase have higher propensities to be measured in the second phase.

USING LEADING INDICATORS TO IDENTIFY PHASE COMPLETION

While Figure 3, showing the hours per interview rapidly increasing at the end of the phase, is *post hoc* evidence that phase capacity has been reached, a more cost-efficient design could be attained if the phase capacity could be predicted before that point. To do this, one would like to assemble leading indicators of phase capacity so that survey managers can halt the phase just at the right moment. In the sections below, we will give examples of active use of such paradata indicators and how we judged the impact of the use. The evidence about changes is not based on experimental findings. As a result, the evidence below might best be viewed as suggestive of the mechanisms that created changes in key outcomes of the survey.

Shifting Attention among Screener Interviews & Main Interviews

When a survey involves a screening step to identify sample households with eligible persons, the attention of the data collection resources are inevitably divided between screening and main interview activities. If main interview requests are delayed until all screening interviewing is completed for the entire sample, interviewers cannot take advantage of the situation where a willing sample person is available at the same time the screening interview is complete. If screening interviews are taken on the very last day of the data collection period, there is lower likelihood that a main interview will be obtained.

The following figures are examples of those found useful. The first (Figure 4) is the mean number of calls made on both screener cases and main cases. There are four lines on the chart. The solid lines correspond to the experience of the main active cases for the 1st and 2nd quarters of the NSFG. The dashed lines correspond to the screener active cases for the 1st and 2nd quarters. The graph shows only a mild positive slope of the mean until the fifth week or so of the data collection period, followed by a steeper curve. The mean number of calls for the main cases are generally smaller than the mean number of calls for the screener cases. There are differences between the quarters, with the 1st quarter showing higher means at any point (this is an artifact of some of the interviewers starting early in the 1st quarter).

The jump in the slope of the mean number of calls in the fifth week or so may reflect the number of screener cases that have not been called at all. The number uncalled rapidly declines in the first four weeks of the data collection period, then flattens. There is competition for the attention of the interviewer as she plans her day. The management directive is (a) to call on all cases at least once before repeated calls on other cases and (b) to use a visit in a segment to make as many calls as possible.

Figure 5 presents a leading indicator of interviews in coming days—the percent of cases that have appointments among the main interview unresolved cases. Note that the percentage is higher in the early days. This is probably a function of two factors: (a) the management emphasis to complete screeners prior to beginning repeated calling on main cases and (b) the tendency for higher percentages of reluctant sample persons among active main cases toward the end of the survey.

The next indicator is the percentage of cases in locked multi-unit structures. These structures have been found to require more calls to obtain

Figure 4. Mean Calls to Active Screener & Main Cases, by Day

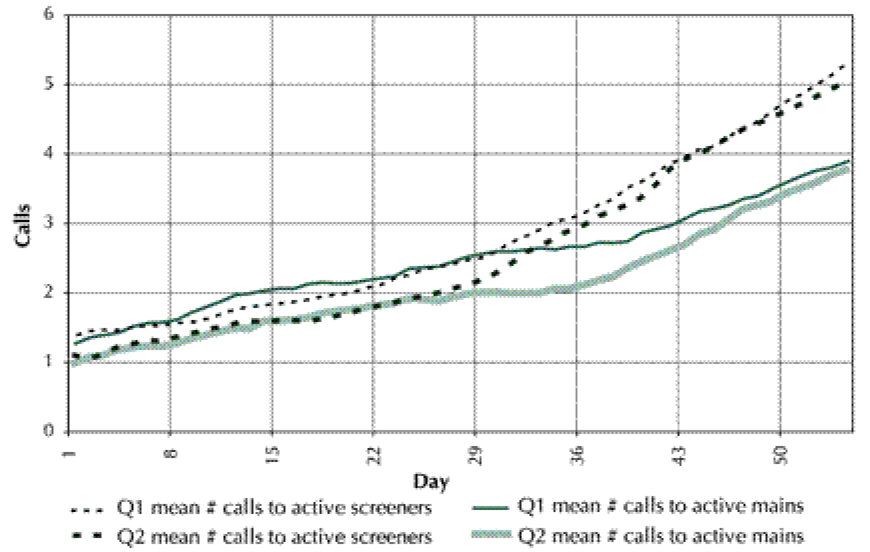


Figure 5. Percentage of Non-finalized Main Cases with Hard Appointments, by Day

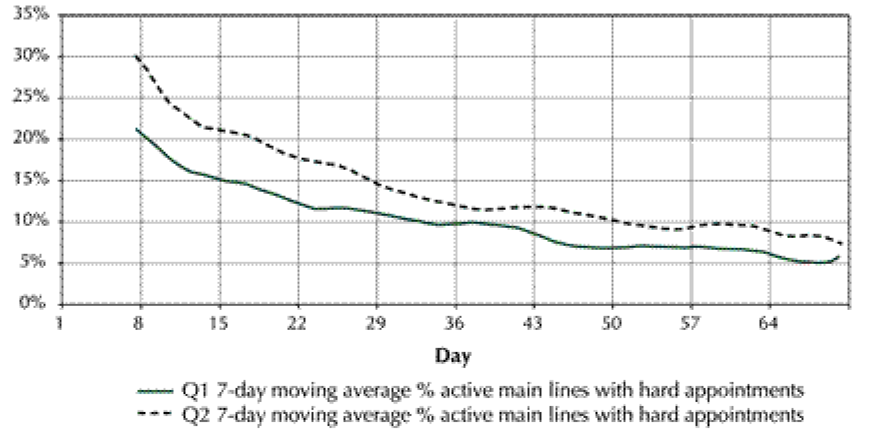
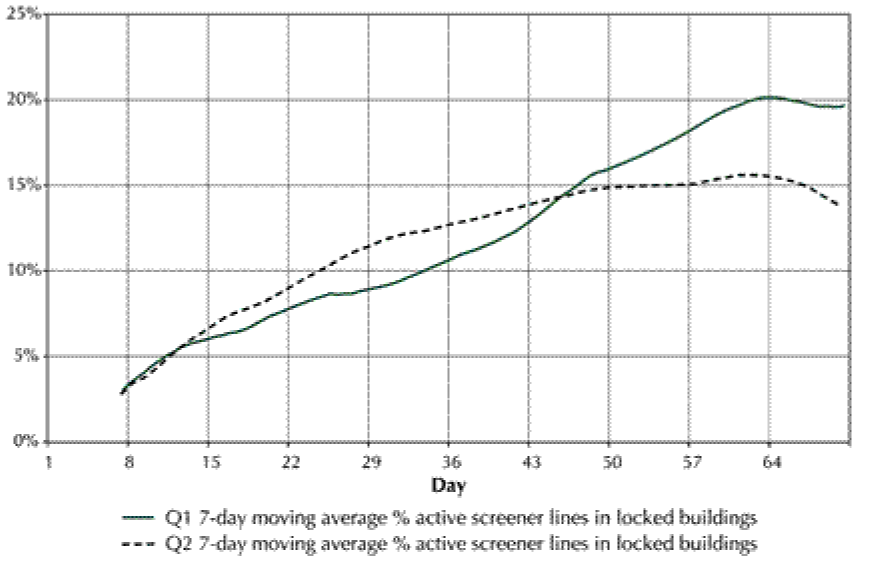


Figure 6. Percentage of Active Screener Cases in Locked Buildings, by Day



interviews and to have lower chances of yielding interviews. Building managers must sometimes be contacted to seek access to the units inside the structure. In Figure 6, you can see variation over the quarters in the shape of the indicator by day of the survey. This was the result of a management intervention to identify locked apartment buildings immediately using the paradata indicators and to front-load the attention to these buildings. This intervention led to smaller percentages at the end of the data collection period in quarter 2.

The next graph (Figure 7) is a leading indicator of higher costs per interview—the percentage of cases that have displayed some resistance during contacts with the interviewer. The top lines show that there is greater resistance to the short screener interview proportionately than to the main interview. This is partly a function of the fact that the only active main cases shown in the graph are those in which successful screeners had been completed. The percentage resistant rises each day of the period, reflecting the fact that cases that are resolved tend to be

Figure 7. Screener and Main Resistance Rate, by Day

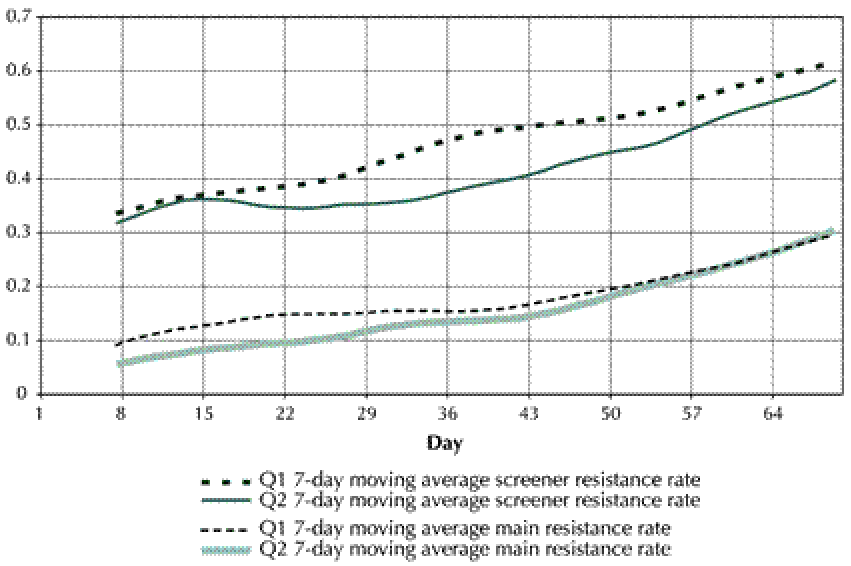


Figure 8. Percentage of Active Screener & Main Cases with 8 or More Calls, by Day

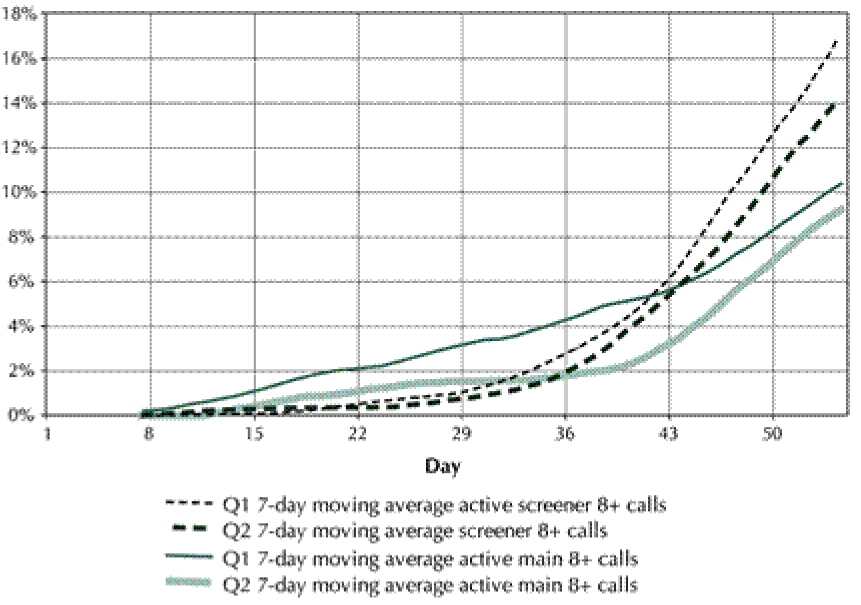
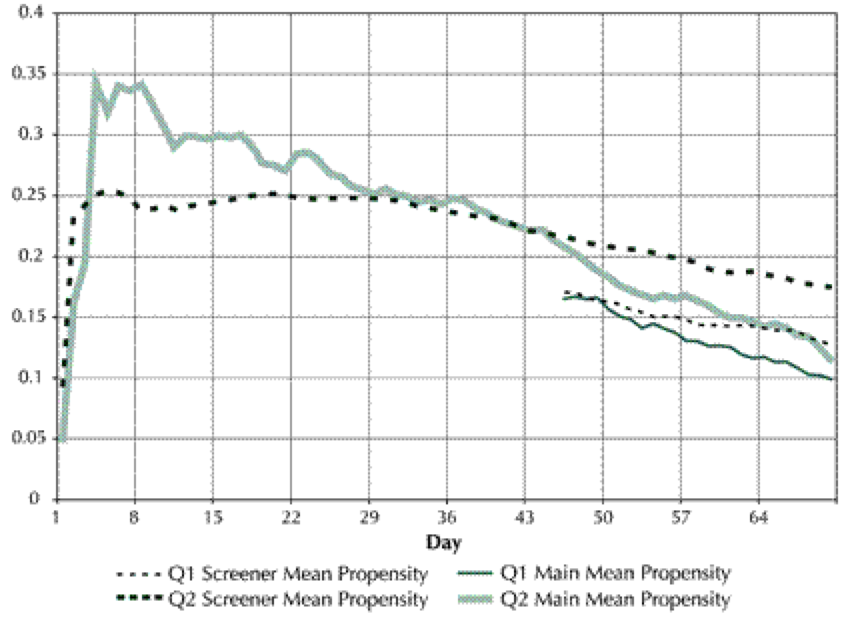


Figure 9. Mean Estimated Probability of Being Interviewed on Next Call for Active Screener & Main Cases, by Day



interviews and to come from persons with less relative resistance to the survey request.

Figure 8 shows the percentage of active cases that have received eight or more calls on the case without finalizing the case. To permit changes over time, the graph is truncated in the middle of the data collection period. Note that the slope rises rapidly after five weeks, when most of the easy screener cases have been called. The screener percentage with many calls rises more dramatically, reflecting management emphasis on calls on the screener.

A common problem is how to calibrate the effort on screener interviewing and main interviewing. One example of using this set of information is a convergence of signals that more attention is needed on main interviewing: mean calls for mains are below past targets but screeners are above, 8+ calls for main are below past targets but screener 8+ calls are higher than past targets, hard appointments for main are below past targets, resistance for mains is below past targets but screener resistance is similar to the past, and the response rate for mains is slipping more than the response rate for screeners.

Using Multivariate Propensity Models During the Data Collection

Given the availability of paradata like those above, call-level discrete hazard models predicting the likelihood of an interview on the next call can be constructed. These include the call-varying covariates like those above as well as fixed attributes of the case that predicts response propensity. These models are estimated each day on the set of unresolved screener cases and main cases (see Groves et al., 2005, for a description of the models). The expected value for each active case can be estimated under the model, and the mean for all active cases monitored each day. Figure 9 presents the mean conditional probability by day of the survey. The propensities were not being estimated daily in the first quarter until late in the quarter, but the general trend is clear. The mean propensity monotonically declines among active cases as the days pass. This reflects the fact that the remaining cases at the end of the survey period are those that are very difficult to measure and require more interview effort to do so.

The screener propensity model is a discrete hazard model with predictors that include urbanicity, residential density of neighborhood, presence of non-English speakers, perceived safety concerns in the neighborhood, physical access impediments for the housing unit, multi-unit status, number of prior calls to the case, whether there was a prior contact on the case, number of prior contacts, whether a household member made statements or asked questions during a prior contact, whether a household member asked a question in the last contact, and whether there was a prior contact with some resistance to the survey request.

The hazard model for the main interviews has predictors that are urbanicity, residential density of neighborhood, presence of non-English speakers, presence of Spanish speakers in the neighborhood, perceived safety concerns in the neighborhood, existence of a prior contact with the sample person, existence of prior resistance to the request, multi-unit status, physical access impediments, and whether the sample person is a teenager, male, non-White, Spanish speaker, or living alone. In addition, measures of prior calls—whether the sample person made statements or asked questions on prior contacts, the number of prior calls, number of prior contacts, and whether there was evidence of resistance—are included.

What is the responsive design use of daily tracking of such conditional probabilities? There is one that has been found to be useful: the stratification of a two-phase sample of nonrespondents using the expected values of the response propensities. This acts to control efficiency of interviewing in the second phase.

Others uses are conceivable, but we have not yet implemented them. As Figure 9 shows, we are finding almost monotonic reduction in the mean propensity among active cases as the days go by. One might speculate that it would be desirable to achieve equal expected propensity over subsets of active cases that vary on key survey variables.

CONCLUSIONS

The use of computer assistance in data collection can lead to enriched data to manage the health survey production process. There are two valuable uses of these data: (a) to identify leading indicators of field problems and successes and (b) to create a system of forecasting tools that will facilitate the use of responsive design interventions to balance the costs and errors of the survey.

REFERENCES

Cochran, W. (1967). *Sampling techniques.* New York: Wiley.

Groves, R. (1989). *Survey errors and survey costs.* New York: Wiley.

Groves, R., & Heeringa, S. (2006). Responsive design for household surveys: Tools for actively controlling survey nonresponse and costs. *Journal of the Royal Statistical Society, Series A, 169,* 439–457.

Kish, L. (1965) *Survey sampling.* New York: Wiley.

Little, R., & Rubin, D. (2002). *Statistical analysis with missing data.* New York: Wiley.

Groves, R. M., Benson, G., Mosher, W. D., Rosenbaum, J., Granda, P., Axinn, W., et al. (2005). *Plan and operation of Cycle 6 of the National Survey of Family Growth* (Vital and Health Statistics, Series 1, No. 42). Retrieved August 3, 2007, from www.cdc.gov/nchs/data/series/sr_01/sr01_042.pdf

Neyman, J. (1938). Contribution to the theory of sampling human populations. *Journal of the American Statistical Association, 33,* 101–116.

Sudman, S. (1967). *Reducing the costs of surveys.* Chicago: Aldine.

Särndal, C.-E., Wretman, J. H., & Swensson, B. (2003). *Model-assisted survey sampling.* New York: Springer-Verlag.

FEATURE PAPER: Design Trade-offs for the National Health and Nutrition Examination Survey

Lester R. Curtin, *Centers for Disease Control and Prevention*
Leyla Mohadjer, *Westat, Inc.*

INTRODUCTION

The National Health and Nutrition Examination Surveys (NHANES) are a series of health-related programs conducted by the CDC's National Center for Health Statistics (NCHS) and carried out under contract with Westat, Inc. As both a descriptive and analytic survey, the NHANES design must balance the trade-offs between cost considerations and statistical considerations. As a descriptive study, statistical considerations include aspects of data quality (response rates), as well as the statistical precision of survey estimates. As an analytic survey, NHANES design also must balance design options that affect hypothesis testing and modeling of the data.

This paper discusses some of the design options and trade-offs in the current NHANES design. First, some background information is presented on the NHANES survey and its basic content, data collection, and sample design. The design trade-offs then are organized as those issues related to trade-offs for PSU selection and those related to trade-off for the within-PSU selection. A discussion follows on the design implications for multipurpose surveys.

NHANES OBJECTIVES, DATA COLLECTION, & SAMPLE DESIGN

A critical aspect of the NHANES data collection is that there are multiple descriptive and analytic objectives for the survey. The main objectives of NHANES are to (1) estimate the national prevalence of selected diseases and risk factors; (2) estimate national population reference distributions of selected health parameters and environmental contaminants; (3) document and investigate reasons for secular trends in selected diseases and risk factors; (4) contribute to the understanding of disease etiology; (5) investigate the natural history of selected diseases; (6) study the relationship between diet, nutrition, environment, genetics, and health; and (7) explore emerging public health issues. Each of these objectives could lead to a different sample design; the NHANES design must balance the analytic requirements across all objectives.

To meet the multiple objectives, NHANES has evolved over time into a unique and complex survey with several stages of data collection: a CAPI household interview, specimen collection within the household (dust, water), and a complete medical examination carried out in mobile examination centers (MECs). Data collection in the MEC consists of interviews, including an audio-CASI for sensitive data, physical measurements, specialized non-diagnostic examinations, and collections of biological specimens (blood, urine, hair, and saliva). After the MEC visit, there may be additional data collection, such as a second-day telephone interview on nutrition, or the sample person may wear a monitoring device for a period of time (a VOC badge to measure exposure or an accelerometer to measure physical activity). To reduce the cost of medical examinations, some MEC components are assigned to random subsamples of the full sample.[Note]

The sample design for NHANES starts with the target population—the noninstitutionalized civilian population of the United States. Active military and institutionalized persons are excluded. Past NHANES surveys were designed as periodic, multiyear cross-sectional surveys. NHANES I was in the field from 1971–74, NHANES II covered 1976–81, and NHANES III covered 1988–94 (Ezzati, Massey, Waksberg, Chu, & Maurer, 1992). The periodic nature of the past surveys left data gaps in the monitoring of health conditions in the U.S. Further, the timeframe to produce national estimates was considered too long. To improve its timeliness and increase its utility, the survey was implemented as a continuous ongoing annual survey beginning with NHANES 1999 (Montaquilla, Mohadjer, & Khare, 1998).

NHANES design requirements call for adequate geographic coverage (that is, a nationally representative sample), prespecified levels of precision for given demographic subdomains, the ability to measure racial/ethnic disparities, and the ability to maintain satisfactory response rates. Each sample design requirement leads to design options that come with trade-offs: advantages and disadvantages in terms of increased or decreased costs, precision, or data quality. As NHANES is a multistage design, we start with the trade-offs in the first stage of selection: that is, defining and selecting the primary sampling units.

TRADE-OFFS IN PSU SELECTION

For NHANES, the primary sampling units (PSUs) often are referred to as “stands” and are selected from a frame of all U.S. counties. This section discusses the design and its implications in terms of definition of PSUs, stratification of PSUs, and the need to cumulate sample over time (as discussed later in the paper).

Definition of PSU & Relation to Response Rates

As with many surveys, NHANES must implement operational and design decisions that help improve response rates. For many household health surveys, current response rates are 90% or above. For the current NHANES survey, the overall response rate for examination coponent is

76%, so the survey cannot tolerate PSU-specific design options that lower the response rates. As such, the PSUs for NHANES typically are defined as individual counties to reduce the amount of travel necessary for respondents to visit a MEC and thereby increase the likelihood of achieving high response rates. Obviously, high response rates are necessary to maintain the quality of the survey estimates. The analytic downside is that this design feature results in more clustering of the population at the first stage of the sample.

The Number of PSUs & Geographic Coverage

One critical feature of a national sample design is determining the number of PSUs. For NHANES, the number of PSUs is determined largely by the need to administer the medical examinations in the MECs. Each MEC is composed of four trailers that are specially designed and equipped and contain all of the medical equipment. MECs travel to survey locations throughout the country. At any one time, two of the three MECs should be operating while the third is being moved to the next location or being renovated. This method of data collection imposes significant limitations on the design of NHANES in terms of the number of PSUs, geographic coverage, and seasonality of estimates.

Past experience has shown that an average of 340 examined persons in 15 locations is the approximate optimum design that provides the maximum number of PSUs while keeping the sample size in each area large enough to justify the costs associated with moving the MECs. Increasing the number of locations would make the annual sample more representative with respect to geography but would increase the travel and set-up time between stands so that fewer than 5,000 persons could be examined. Reducing the number of stands per year would reduce travel and set-up time and therefore allow for more than 5,000 persons per year, but doing so would increase clustering and further reduce the geographic coverage of the annual sample.

MEC data collection creates another issue. The annual schedule for the traveling MECs needs to be established ahead of time. Since there is a risk of MECs not being able to function in areas with adverse weather, it is critical to schedule the data collection in the PSUs during good-weather months. Not only would it be much more costly to equip the MECs to operate under severe weather conditions, but the sample person response rates also would suffer. After selection, the stands/PSUs are scheduled so that the MECs are in the Northeast and Midwest in warmer weather and in the South and Southwest in colder seasons. This creates a seasonality (and a seasonality by geographic interaction) issue for the data collection.

For most NHANES analytic objectives, seasonality is not an issue. In planning for new analytic objectives, it is recommended not to measure the relevant component through NHANES if seasonality is an overriding analytic concern for the proposed health objective. Still, some objectives in NHANES do have seasonality issues, such as some nutrition objectives and the relationship of vitamin D to the development of osteoporosis.

Impact of a Design with 15 PSUs per Year

As mentioned above, a unique feature of NHANES is the complete medical examinations carried out in the MECs. The combination of budget constraints and the need to have MEC examinations impose the limitation of 15 PSUs per year. This affects the survey objectives in a number of ways, specifically (1) the trade-off between oversampling racial/ethnic groups and geographic coverage, and (2) the need to have a design that allows analysts to combine several years of survey data to meet some analytic objectives.

Minority populations are not uniformly distributed across the U.S. There is a certain amount of geographic clustering by region of the country and by urban/rural classification. In the NHANES design, PSUs (and to some extent, secondary sampling units) are selected from frames that have been stratified by the proportion of minority population. The PSU frame is stratified by the four census regions, metropolitan status, and minority density, but design-based subnational estimates, such as census division or states, are not particularly feasible even when a number of years are combined. Of particular note, the survey is not specifically designed to ensure that survey participants are representative for other user-defined geographic regions. For example, recent analysis of NHANES data has grouped PSUs into areas such as "U.S.-Mexico border states" or "coastal counties." NHANES was not designed to be specifically representative with respect to those defined areas, and the number of PSUs in each area is small. Considerable caution should be exercised if using NHANES in this manner. As in most national surveys, the NHANES design must balance the need for statistical efficiency for racial/ethnic subdomains with geographic coverage, and the data user *must* understand the design in order to properly interpret the results.

Data Release, Confidentiality, & Combining Data Over Time

Although NHANES is designed as an annual sample, most analytic objectives require at least two years of data to provide sufficient sample size and geographic coverage. NHANES releases data in two-year data cycles with sample weights that correspond to the midpoint of the two-year interval. The two-year data release comes with a price, in that it creates a confidentiality problem. With only 30 PSUs in a two-year cycle and with extensive advance arrangements and publicity to increase response rates, small counties could easily be identified through information needed for variance estimation. Fortunately, research has shown that masked variance units (MVUs) can be constructed. These MVUs mask the geography while allowing reasonable estimation of sampling errors (Park, Dohrmann, Montaquilla, Mohadjer, & Curtin, 2006).

One of the main analytic limitations of an NHANES annual sample is the small number of PSUs, which results in a small number of degrees of freedom for variance estimation and analysis. Thus, design-based variance estimates are relatively imprecise. Additionally, the sample sizes for most of the analyses of interest are too small in annual samples. Most analyses will need to accumulate a number of annual samples for their analysis purposes. While the two-year cycle is adequate for most objectives, some objectives related to small domains or rare events require combining multiple years of data. Thus, it is critical to employ a sample design that allows efficient accumulation of the annual samples across years.

One way to achieve nationally representative annual samples would be to select an independent sample of PSUs each year. For NHANES, due to the limited number of PSUs and the fact that PSUs are selected proportionate to size, this approach likely would lead to substantial overlap in PSUs from year to year. Sample overlap, even at the PSU level, could lead to loss of precision of survey estimates when survey years are combined (due to increased clustering of the sample). Thus, rather than sampling PSUs independently each year, a specific stratification scheme was adopted. Starting in 2002, each major stratum for PSUs is divided further into six minor strata. Within each major stratum, one PSU is selected from each minor stratum and then randomly assigned to a particular sample. After six samples of PSU have been drawn, they are randomly assigned to specific calendar years. The stratification scheme is designed to ensure that the PSUs comprising the annual and multiyear samples are distributed evenly in terms of geography and certain population characteristics, specifically by race/ethnicity.

The most recent selection of PSUs was completed for the four-year period 2007–2010. As such, four instead of six minor strata were defined. The shift from a six- to a four-year independent design was based on the need to ensure rolling four-year samples to correspond to certain content needs of the current survey.

TRADE-OFF FOR WITHIN-PSU SELECTION

In addition to design trade-offs in the first stage of selection, other stages also are designed to aid in oversampling subdomains while focusing on increasing response rates. For the current NHANES design, the second sampling stage is area segments comprised of census blocks or combinations of blocks. Segments are selected with PPS, with an average of 24 segments sampled. The third stage of sample selection consists of households and noninstitutional group quarters, such as dormitories. All dwelling units (DUs) in the sampled segments are listed, and a subsample of households and group quarters within the DUs are designated for screening to identify potential sample persons (SPs) for interview and examination. SPs within the households or group quarters are the fourth stage of sample selection. Of particular note, in NHANES, there is typically more than one person per household selected.

Number of Sample Persons per Household

The sample is selected to maximize the average number of sample persons per household because it appeared to increase the overall response rate in previous surveys. One of the factors thought to be responsible for the increased response rates in multiple-SP households is that each person is given remuneration for his or her time and participation, and it is generally more convenient for household members to come to the MEC at the same time. A more detailed description of the within-PSU sample design can be found in Mohadjer and Curtin (2006).

The effect of within-household clustering is not a large concern for NHANES because most analyses are done within subdomains (or some limited groups of subdomains), and there is generally little within-household clustering at the subdomain level. However, the inclusion of more than one person per household reduces the effective sample size for estimates for the total population.

Total Population vs. Domain Estimates

One of the more intriguing design trade-offs for NHANES is the trade-off in the precision of estimates for the total population versus estimates for specific demographic subdomains. Most analyses of NHANES data are conducted for defined age categories within various socioeconomic subgroups of the population. Therefore, the survey uses differential probabilities of selection (i.e., oversampling) to produce efficient sample sizes for 72 specific subdomains of the U.S. population.

An equal probability or self-weighting national design should yield a sample with about 12% non-Hispanic Blacks and 8% Mexican Americans. With geographic stratification at the PSU and secondary sampling levels and with extensive screening and differential probabilities of selection at the household level, NHANES is able to select about 23% Black and 31% Mexican Americans in the (unweighted) sample. Furthermore, a self-weighting design would result in a sample with 30% under age 20, 55% between 20 and 65, and 15% over age 65. The NHANES sample is 47% under 20 and 20% over age 60; the trade-off is that the 20–59 age group is only 33%. Still, the number of sample persons 20–59 is considered adequate to obtain the required precision.

Typically, sampling errors for estimates for the total population are increased due to unequal probabilities of selection as well as the clustering previously mentioned. For a multistage cluster design with differential weighting, the DEFF (ratio of complex variance to a hypothetical simple random sample variance) can be given as

$$\text{DEFF} = (1 + \text{CV}^2{}_{\text{wts}})*(1 + [m - 1]\text{r}),$$

where $\text{CV}^2{}_{\text{wts}}$ is the coefficient of variation of sampling weights, m is the average cluster size, and r is the intraclass correlation coefficient.

For a population total, the sampling weights in NHANES are highly variable, resulting in increased sampling errors. Similarly, the average cluster size is larger for estimates of a total population than for a subdomain. The actual DEFF depends on the r, and this varies considerably by the health outcome measured. While the DEFF for subdomains typically range from 1.1 to 2.5, the corresponding DEFF for the totals population ranges from 2.0 to about 8.0 (some laboratory values can have much larger DEFF). This is an NHANES design trade-off: the statistical requirements for subdomains have higher priority than the statistical requirements for the total population estimates.

DISCUSSION

The NHANES is an extremely valuable multipurpose survey that provides unique information on the nation's health. It is the primary source for national nutritional data, the only source of measured obesity, the only source of data on undiagnosed diabetes, and a primary source for national human exposures on environmental measures. It is necessary to devote substantial attention to the development and maintenance of an efficient sample design for a survey with such an extensive set of objectives. Designing a survey to meet these multiple objectives is challenging—more so when budget and operational constraints limit the survey to 15 PSUs and 5,000 examined persons per year.

Within these constraints, the NHANES sample is designed to select a nationally representative annual sample as well as cumulated samples across years. Overall, the sample design is balanced on the need for a two-year data release cycle, adequate response rates, and geographic coverage, in addition to the need for relatively precise racial/ethnic subdomain estimates. The sample is designed to produce efficient sample sizes for a large number of demographic subdomains of the U.S. population, rather than an estimate for the total U.S. population, because most analyses of NHANES data are conducted for defined age categories within various demographic and socioeconomic subgroups of the population. This leads to an interesting trade-off in the perceived efficiency of the sample design.

For some objectives, such as estimating the proportion overweight or obese in the population, sample size and precision is adequate for the detailed demographic subdomains used in the design. For other objectives, such as diabetes prevalence, a single-year or two-year estimate may have sufficient sample size for broad demographic subdomains. For broad demographic subdomains, the sample design effects are larger due to an increase in the differential weighting and increased clustering. When design effects are used as a measure of design efficiency, it appears as though the two-year NHANES sample is more inefficient for diabetes prevalence than for overweight prevalence. However, when four years of data are combined for diabetes prevalence, then sample size is adequate for the more detailed demographic subdomains and the design effects are smaller.

Of course, there are instances in which the analytic objective concerns a rare event or is focused on a small segment of the population. In such a case, the national design may not produce the desired effective sample size for that single objective with even four data years. Thus, the design must be able to cumulate sample over longer time intervals. Current plans are to continue to select the PSUs as independent four-year samples that create both annual and two-year national samples that can be cumulated to form four-, six-, or even eight-year estimates.

To summarize, for NHANES, the combination of the study's complexity and the examination of only 5,000 persons per year leads to a number of design trade-offs. The emphasis of NHANES is on subdomain estimates at the expense of some efficiency for total population estimates. Operational and scheduling constraints create a sample that is not balanced for seasonality. Oversampling for racial/ethnic domains somewhat limits the geographic coverage of the sample unless several years are cumulated. Measures to improve response rates impact the design efficiency for some estimates, enhancing the efficiency for others, while creating potential disclosure problems. Disclosure problems associated with a timelier two-year data release cycle limits the public release of some data items and places these data items into nonpublic data sets available only in the NCHS Research Data Center.

Despite the design trade-offs, the NHANES is a very efficient design given the design specifications. Caution is advised when analyzing data outside of the design specification (e.g., making subnational estimates, measuring seasonal effects, and ignoring design information in more sophisticated statistical analyses).

REFERENCES

Ezzati, T., Massey, J., Waksberg, J., Chu, A., & Maurer, K. (1992). Sample design: The third National Health and Nutrition Examination Survey (DHHS Publication No. 92-1387). *Vital and Health Statistics, 2*(113).

Mohadjer, L., & Curtin, L. R. (2006, November). *Challenges in the design of the National Health and Nutrition Examination Survey.* Paper presented at the 23rd International Methodology Symposium, Gatineau, Quebec.

Montaquila, J., Mohadjer, L., & Khare, M. (1998). The enhanced sample design of the future National Health and

Nutrition Examination Survey (NHANES). In *Proceedings of the Survey Research Methods Section* (pp. 662–667). Alexandria, VA: American Statistical Association.

Park I., Dohrmann S., Montaquilla J., Mohadjer, L., & Curtin, L. R. (2006). Reducing risk of data disclosure through area masking limiting biases in variance estimation. In *Proceedings of the Survey Research Methods Section* (pp. 1761–1767). Alexandria, VA: American Statistical Association.

[Note] All data collection forms and data collection protocols are available on the NHANES Web site: www.cdc.gov/nchs/nhanes.htm

FEATURE PAPER: A Simulation Model as a Framework for Quantifying Systematic Error in Surveys[Note]

James A. Singleton, Philip J. Smith, Meena Khare, and Zhen Zhao, *Centers for Disease Control and Prevention*
Kirk Wolter, *National Opinion Research Center*

INTRODUCTION

Systematic error in surveys can result from noncoverage of the target population by the sampling frame, nonresponse at multiple stages of the survey, and measurement error. Increasing prevalence of households that have substituted a wireless telephone for their residential landline telephone has decreased coverage of households in random-digit-dial (RDD) telephone surveys (Blumberg, Luke, & Cynamon, 2006). Response rates to RDD surveys have been declining (Battaglia et al., in press; de Leeuw & de Heer, 2002; Link, Mokdad, Kulp, & Hyon, 2006; Smith, Hoaglin, Battaglia, Khare, & Barker, 2005). Decreased frame coverage and lower response rates may increase the potential for bias in overall survey estimates or in estimates for geographic or sociodemographic subgroups. The declining trends in response rates reinforce the importance of efforts to evaluate and reduce systematic errors in RDD survey estimates. For example, the Office of Management and Budget requires that all federally sponsored data collections include a description of plans to evaluate nonresponse bias when the expected overall response rates are below 80% (Graham, 2006).

A systematic review of thirty published articles with nonresponse rates ranging from approximately 15–70% shows that nonresponse bias does occur when characteristics of respondents are not similar to nonrespondents, but the nonresponse rate of a survey is not a good predictor of the magnitude of nonresponse bias (Groves, 2006). In fact, efforts to increase response rates (e.g., use of incentives) could sometimes increase nonresponse bias. Thus, it has been recommended that efforts to reduce bias in final survey estimates should focus on strategies to minimize differences between respondents and nonrespondents, understand these differences, and evaluate methods to adjust for them (Groves & Couper, 1998).

Nonresponse (or selection) bias occurs if the likelihood of responding is associated with the outcomes of interest. This can be assessed directly if it is possible to obtain outcome data for a random sample of nonresponders. Selected indirect approaches include comparison of respondent-reported sociodemographic characteristics or other variables with those estimated from a population census or survey with higher response rates (Groves, 2006), using hard-to-reach respondents as proxies for nonresponders (Skalland, Wolter, Shin, & Blumberg, 2006), and ecologic analysis comparing respondents and nonrespondents based on census measures compiled by telephone exchange or place of residence (e.g., ZIP code; Johnson, Cho, Campbell, &

Holbrook, 2006). Unless direct comparisons of respondents and nonrespondents are available, reports of survey results may address systematic error by reporting response rates and making qualitative statements about bias that may remain after weighting adjustments for noncoverage and unit nonresponse.

Some recent papers have proposed new methods for sensitivity analysis to assess systematic error in observational studies (Greenland, 2005; Lash, 2006; Lash & Fink, 2003; Phillips, 2003). These methods use Monte Carlo simulations to simultaneously correct for multiple selection, confounding, and information biases, using externally derived distributions of bias levels. The outcome of this method is an estimated probability distribution for the bias-corrected outcome measure, reflecting both random and systematic error. A similar approach has been applied to survey data (Hogan & Wolter, 1988; Mulry & Spencer, 1991). These methods offer an approach for quantifying threats to validity in nonrandomized observational studies and can be applied to probability-based sample surveys as well. Having an estimate of the putative probability distribution of systematic errors in a survey would help in interpretation and user confidence in survey estimates.

The purpose of this paper is to describe an application of the Monte Carlo simulation-based sensitivity analysis approach (Lash & Fink, 2003) for assessing nonresponse bias in the National Immunization Survey (NIS). We focus on noncoverage and nonresponse bias. This approach also can be expanded to assess measurement errors and confounding. We show how information from multiple types of nonresponse bias assessment studies can be synthesized to provide a quantitative assessment of noncoverage and nonresponse bias.

THE NATIONAL IMMUNIZATION SURVEY

The NIS was established in 1994 and provides estimates of vaccination coverage rates among children age 19–35 months for each of the fifty states and selected large urban areas. These data are used to evaluate immunization grant programs, identify underimmunized sub-populations, and determine needs for the Vaccines for Children Program (Salmon et al., 2006). The NIS targets children age 19–35 months living in U.S. households at the time of the survey. The survey is conducted in two phases: (1) an RDD survey to identify households with age-eligible children, collect information about the child's vaccination history and sociodemographic information, and collect contact information for the child's vaccination providers; and (2) a mail survey to collect the child's vaccination histories from providers and information about the provider's practice. Provider-reported vaccination histories deemed sufficiently complete are used to estimate vaccine coverage rates. Sample weights are adjusted for probability of selection of telephone numbers, unresolved telephone numbers, nonresponse to the age-eligibility screener and household interview, lack of consent given to contact providers, multiple phone lines per household, noncoverage of households with no landline telephones, nonresponse to the provider mail survey, and noncoverage of population subgroups (Smith et al., 2005).

In 2005, a sample of 4.5 million telephone numbers was released (see Table 1). Of these, 83.3% were resolved as residential or non-residential. Among identified households, age-eligibility screening was completed for 92.8%. Among households successfully screened for eligibility, the interview completion rate was 84.2% for age-eligible children. Multiplying these three response rates yields a CASRO response rate of 65.1% (Battaglia et al., in press; Ezzati-Rice et al., 2000). The resolution, screener, and interview rates declined over the twelve years of the NIS (1994–2005). In the third year of the survey (1996), the resolution, screener, interview, and CASRO rates were 94.3%, 96.8%, 94.0%, and 85.8%, respectively. In addition, the proportion of screened households determined to have an age-eligible (19–35 months old) child declined from 3.9% in 1996 to 3.2% in 2005. In the 2000 Census, 5.2% of U.S. households had a child age 19–35 months, indicating that some screened households do not indicate they actually have an age-eligible child, the observed eligibility rate among screened households may be lower than the unobserved rate among unscreened and unidentified households, or the eligibility rate among households with landline telephones has decreased over time.

Because less than 50% of the children have household-reported vaccination histories from the written shot-card from the providers, the NIS relies on provider-reported vaccination histories to assess vaccination coverage, introducing further opportunity for nonresponse. Among children with completed interviews in 2005, parental consent to contact identified providers was obtained for 78.5%; this rate ranged from 84–88% during 1996–2004. Of providers who were mailed an immunization history questionnaire with child's name, gender, and date of birth, 88% returned completed forms in time for the annual data file and estimates. Among children with completedinterviews, adequate provider data was available for 63.6%. Multiplying this rate with the CASRO rate yielded a combined response rate for the two survey phases of 41%, without accounting for possible underascertainment of eligible households at the screener or earlier stages. A detailed analysis of noncoverage and nonresponse rates at each stage of the 2002 NIS has been reported, along with evaluation of the definition of adequate provider data that includes some children for whom not all identified providers responded (Smith et al., 2005). The NIS uses response propensities to form adjustment cells and compensates for differences between children with completed interviews for whom adequate provider data was and was not collected; the overall extent of bias reduction from this approach is low (0.5% in 1998; Smith et al., 2001). However, the potential nonresponse bias in the NIS estimates across all survey stages has not been quantified.

Table 1. Selected Operational Results of Data Collection, National Immunization Survey, 2005

Row	Key Indicator	Number	Percent
RDD Phase			
1	Total selected telephone numbers in released replicates	4,465,261	-
2	Telephone numbers resolved before release to the telephone centers	1,871,599	41.9% (Row 2/Row 1)
3	Total telephone numbers released to the telephone centers	2,593,662	-
4	Advance letters mailed	1,460,066	56.3% (Row 4/Row 3)
5	Resolution rate: Resolved telephone numbers*	3,721,224	83.3% (Row 5/Row 1)
6	Households identified	1,085,040	29.2% (Row 6/Row 5)
7	Screening completion rate: Households successfully screened for presence of age-eligible children	1,006,435	92.8% (Row 7/Row 6)
8	Households with no age-eligible children	974,510	96.8% (Row 8/Row 7)
9	Eligibility rate: Households with age-eligible children	31,925	3.2% (Row 9/Row 7)
10	Interview completion rate: Households with age-eligible children with completed household interviews	26,867	84.2% (Row 10/Row 9)
11	CASRO response rate**	NA	65.1% (Row 5 x Row 7 x Row 10)
12	Age-eligible children with completed household interviews***	27,627	-
Provider Record Check Phase			
13	Children with consent to contact vaccination providers	21,692	78.5% (Row 13/Row 12)
14	Immunization history questionnaires mailed to providers	27,023	-
15	Immunization history questionnaires returned from providers	23,767	88.0% (Row 15/Row14)
16	Children with adequate provider data	17,563†	63.6% (Row 16/Row 12)

*Includes telephone numbers resolved before release to the telephone centers (Row 2).
**Council of American Survey Research Organizations.
***Rows 12–16 exclude children found to be ineligible based on the provider-reported date of birth.
†Includes 115 unvaccinated children.

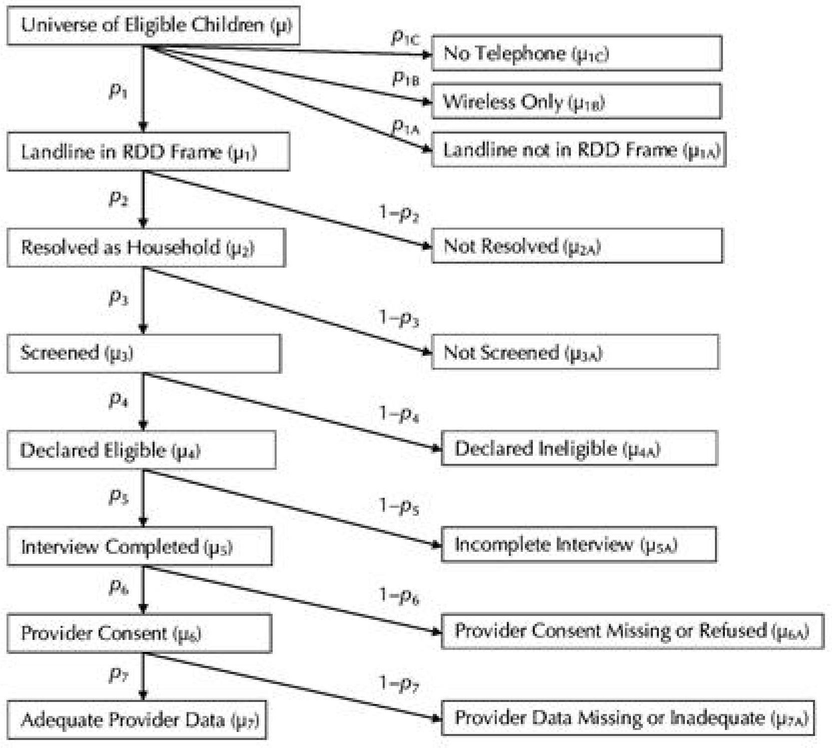
SENSITIVITY ANALYSIS USING MONTE CARLO SIMULATION MODEL

Model Structure & Assumptions

In the NIS, the primary outcome of interest is for a child to be up-to-date (UTD) with a particular vaccine or series of vaccines by the time of the NIS household interview. We describe the model for a generic choice of vaccine or vaccine series. The universe for the model is defined as the population of eligible children age 19–35 months living in the U.S. At the first (coverage) stage of the model, these children are stratified by household access to landline telephone included in the RDD frame, landline telephone not included in the RDD frame, wireless phone only, and no access to telephone. Those living in households with landline phones included in the RDD frame are further allocated into respondent and nonrespondent groups at six subsequent stages of the survey (resolution, screening, eligibility declaration, interview, consent to contact providers, and provider response). Table 1 shows the response rates at various stages of the survey from the recent NIS, and Figure 1 displays the model structure for the sensitivity analysis in a flow diagram.

Let Y_i be an up-to-date (UTD) variable of interest for the ith child in the eligible population for either an

Figure 1. Sensitivity Analysis Model


Universe of Eligible Children (μ)
p1C
No Telephone (μ1C)
p1B
Wireless Only (μ1B)
p1A
Landline not in RDD Frame (μ1A)
p1
Landline in RDD Frame (μ1)
p2
1−p2
Not Resolved (μ2A)
Resolved as Household (μ2)
p3
1−p3
Not Screened (μ3A)
Screened (μ3)
p4
1−p4
Declared Ineligible (μ4A)
Declared Eligible (μ4)
p5
1−p5
Incomplete Interview (μ5A)
Interview Completed (μ5)
p6
1−p6
Provider Consent Missing or Refused (μ6A)
Provider Consent (μ6)
p7
1−p7
Provider Data Missing or Inadequate (μ7A)
Adequate Provider Data (μ7)

individual vaccine or a vaccine series. The UTD vaccination rates at each stage $x = 1,2,3,\dots,7$ are denoted by μ_x for respondent groups, and μ_{xs} for nonrespondent groups (at the coverage stage, $x = 1$ and s = subgroup based on household telephone status, having values A = landline not in RDD frame, B = wireless phone only, or C = no access to telephone; for other stages, $x = 2,3,\dots,7$, s = A to denote the subgroup lost to follow-up at the xth survey stage). Conditional probabilities of falling into the next stage x and subgroup s, respectively, are denoted by p_x, $x = 1,2,3,\dots 7$, and p_{xs}, with s as defined above. The model allows for inclusion of households with an age-eligible child where a respondent does not report the age-eligible child and therefore are classified as not eligible. The vaccination rate that is computed for children with adequate provider data is μ_7. Using Figure 1, it can be seen that the vaccination rate among the universe of eligible children (μ) can be decomposed into a weighted average of the vaccination rates for the children with adequate provider data (observed) and for children in the nonresponse groups at each survey stage (unobserved):

$$\mu = p_1\mu_1 + p_{1A}\mu_{1A} + p_{1B}\mu_{1B} + p_{1C}\mu_{1C} \text{ (coverage stage),} \quad (1)$$

where

$$\mu_1 = (1-p_2)\mu_{2A} + p_2(1-p_3)\mu_{3A} + p_2p_3(1-p_4)\mu_{4A} + p_2p_3p_4(1-p_5)\mu_{5A} + p_2p_3p_4p_5\mu_5 \text{ (RDD stage),} \quad (2)$$

and

$$\mu_5 = p_6p_7\mu_7 + p_6(1-p_7)\mu_{7A} + (1-p_6)\mu_{6A} \text{ (interview and provider data stage).} \quad (3)$$

Given values of the conditional probabilities and UTD vaccination rates, the model-based estimates of vaccination rate in the universe of eligible children can be computed and compared to the unweighted and weighted vaccination rate among children with adequate provider data. Since vaccination rates among nonrespondent groups are not known, we can postulate probability distributions that reflect the uncertainty in their true values. It may be possible to derive the probability distribution of μ given certain postulated probability distributions for the vaccination rates in the nonresponse groups. We propose Monte Carlo simulation to sample from the postulated distributions. Note that we ignore random error introduced by sampling.

Table 2. Prevalence of Children Age 1–3 Years Living in Landline, Wireless Phone Only, & Phoneless Households, by Selected Characteristics, National Health Interview Survey, 2005

CHARACTERISTIC	LANDLINE TELEPHONE SERVICE	HOUSEHOLDS W/O LANDLINE SERVICE	
		Wireless only	Phoneless Household
All Children (*n* = 4,329)	86.9%	9.7%	3.4%
Race/Ethnicity			
Hispanic	82.6	12.0	5.4
White, non-Hispanic	89.6	8.0	2.4
Black, non-Hispanic	81.6	14.0	4.4
Multiracial, non-Hispanic	80.9	13.7	5.4
All other, non-Hispanic	95.0	4.0	1.0
Household Size			
2	65.5	23.3	11.2
3	84.2	12.1	3.7
4+	88.8	8.3	2.9
Living Arrangement			
Rented house	75.2	17.7	7.1
Owned house or being bought	93.9	5.3	0.8
Other living arrangement	76.0	14.1	9.8
Health Insurance Status			
Uninsured	77.2	16.2	6.6
Insured	87.8	9.2	3.0
Income to Poverty Ratio			
Income below poverty level <100%	75.4	16.4	8.3
Poverty level 100–199%	80.2	16.8	3.0
Poverty level 200–399%	89.6	9.0	1.4
Poverty level >400%	97.4	2.6	0.0
Residence			
Urban area	86.2	10.2	3.6
Rural area	89.4	8.2	2.4

The proportionate distribution of the universe of eligible children by telephone status, including landline only ($p_1 + p_{1A}$), wireless only (p_{1B}), or no phone access (p_{1C}), will be based on respective proportions of households with age-eligible children from the recent National Health Interview Survey (NHIS). For example, Table 2 shows the prevalence of having access to landline telephone, access to wireless only phone, and no phone access from the 2005 NHIS. The landline population can be further subdivided into those in (p_1) and not in (p_{1A}) the RDD sampling frame. We assume here that conditional probabilities are fixed (e.g., observed from the 2005 NIS: p_7 = P{adequate provider data | provider consent}; p_6 = P{provider consent | completed interview}; and p_5 = P{interview completed | screened and declared eligible}.

Because the observed eligibility rate among screened households is lower than expected (e.g., 3.2% for the NIS in 2005 vs. 4–5% in the U.S.), some eligible households may not declare a child's eligibility during the screening, or eligible households may be resolved or screened at lower rates than ineligible households. The model will allow for a different vaccination rate for children from eligible households that declare eligibility during the screener compared to those for whom eligibility is not declared. The model includes three conditional probabilities related to resolution of cases as households, screening, and declaration of eligibility: p_2 = P{resolved | eligible}; p_3 = P{screened | resolved and eligible}; and $p_{\mathbf{4}}$ = P{declare eligible | resolved, screened and eligible}. These three conditional probabilities can be expressed in terms of resolution, screening and residential rates, the estimated population eligibility rate, and the eligibility rates among resolved and screened households:

p_2 = P{R} * P{HH|R} * **P{E|R,HH}** / P{E|HH} * P{HH} (4)

p_3 = **P{E|R,S,HH}** * P{S|R,HH} / **P{E|R,HH}** (5)

p_4 = P{dE|R,S,HH} / **P{E|R,S,HH}** (6)

The following quantities can be obtained from the NIS: P{R} = resolution rate, P{HH|R} = residential rate among resolved households, P{S|R,HH} = screener completion rate among resolved households, and P{dE|R,S,HH} = proportion of resolved screened households that declare eligibility. The quantity P{E|HH} is the population eligibility rate among households with landlines sampled from the RDD frame, which can be obtained from the NHIS or other sources. The quantity P{HH} is the proportion of telephone numbers sampled from the RDD frame that represent households, which must be estimated or treated as random with a postulated probability distribution. The remaining two probabilities will be treated as random with postulated probability distributions: **P{E|R,HH}** = eligibility rate among resolved households and **P{E|R,S,HH}** = eligibility rate among resolved, screened households. Assuming these two probabilities are both equal to the eligibility rate among households, p_3 becomes a function of observed rates, and p_4 becomes the ratio of the observed eligibility rate and the population eligibility rate. However, it is possible that p_4 = 1, implying that eligible households resolve or screen at different rates than noneligible households.

Postulating Probability Distributions for Vaccination Rates among Unobserved Groups

An analysis of the NHIS data could be used to obtain possible choices for probability distributions for vaccination rates in wireless-only (μ_{1B}) and no-phone-access (μ_{1C}) households. A logistic regression model predicting UTD vaccination status will be fit using NIS data, with candidate covariates that are available in both NIS and NHIS data sets. The fitted model will then be applied to the NHIS landline-only, wireless-only, and no-phone-access households to simulate vaccination status in each group. The differences between simulated vaccination coverage in wireless only vs. landline only and no phone access vs. landline only will be computed. The resulting distributions of differences in vaccine coverage will be used for the Monte Carlo simulation. In one run of the simulation, a value will be drawn from each of these difference distributions, and then the model-based estimate of the vaccination rate among the universe of eligible children (μ) will be computed (e.g., assuming $p_{1A} = 0$ and using the current value of μ_1 based on previous survey stages, $\mu = p_1\mu_1 + p_{1B}[\mu_1 + \text{difference}_B] + p_{1C}[\mu_1 + \text{difference}_C]$).

Completed household interview data are available to guide choices for probability distributions for proportions of children with a completed interview but missing or denied consent to contact providers (μ_{6A}) and with consent to contact provider but provider data are missing or inadequate (μ_{7A}). First, a logistic regression model predicting UTD vaccination status will be fit using children with adequate provider data, including covariates shown to be associated with vaccination and household-reported UTD status. The fitted model then will be used to compute vaccination status for children in groups 6A (completed interview but consent to contact providers not obtained) and 7A (completed interview with consent to contact providers but provider data missing or inadequate), and vaccination coverage computed for each simulation. The distribution of computed vaccination coverage estimates will be used in the simulation to draw values for μ_{6A} and μ_{7A}. This approach is similar to the response propensity method currently used in NIS adjustments for nonresponse at these stages, which assumes data are missing at random within response propensity weighting classes. To allow some degree of violation of this assumption, the simulated values for μ_{6A} and μ_{7A} can be multiplied by a constant factor. Another approach would be to include telephone-exchange-level sociodemographic variables in the logistic regression model, to see if these ecologic variables add predictive value after controlling for individual level factors. Or, vaccination status based on shot records could be compared between children with and without consent or adequate provider data, among the subset for whom parents reported vaccinations from a shot record during the household interview.

Only telephone-exchange-level ecologic variables will be available for the four nonrespondent groups without completed interviews (2A = not resolved, 3A = not screened, 4A = declared ineligible, and 5A = incomplete interview). Using children with adequate provider data, a logistic regression model will be fit to predict UTD vaccination status based solely on exchange-level covariates. This model can then be used to simulate vaccination status among children with incomplete interviews and then to compute vaccination rates. The distribution of vaccination rates would be used in the simulation to draw a value for μ_{5A}. A similar approach can be used to draw values for screened eligible children declared ineligible (μ_{4A}), children in resolved households that were unscreened (μ_{3A}), and children in households that were unresolved (μ_{2A}). However, the simulation would have to be done on the pooled cases: declared ineligible (actually eligible and ineligible), not screened (eligible and ineligible), and not resolved (eligible, ineligible, not household).

To provide additional information about nonresponse at different stages, level of effort analysis will be conducted, similar to the approach described in Skalland et al. (2006) using number of call attempts. This will provide information about potential bias at resolution, screener, and interview stages. Specifically, estimated vaccine coverage among children with adequate provider data will be examined by number of call attempts: until resolution, between resolution and screener, between screener and interview completion, and between interview completion without provider consent until provider consent. Bias will be estimated as the difference between estimated vaccination rates for low- versus high-burden responders. Similar analysis could be done using incentive cases, implemented in the NIS in 2006 for cases that were partially through the screener, that dropped out initially during the interview, or that completed the interview without giving consent to contact providers.

Another potential source of information will be a study of the use of immunization information systems (IIS) in two states as sampling frames for the NIS. Briefly, the NIS interview and provider record check procedures will be conducted on random samples of 19–35 month old children selected from each IIS. The vaccination rates as measured by the IIS will be determined for response and nonresponse groups to estimate bias at the screener and subsequent stages. Although the two selected IIS to be studied have high provider participation, they are unlikely to have 100% complete vaccination histories, and it is possible that completeness of vaccination histories on the IIS may be correlated with likelihood of response at some stages to the NIS survey.

To assess the overall noncoverage and nonresponse bias across RDD survey stages, weighted NIS estimates among households with completed interviews of selected variables available on both NIS and NHIS and associated with vaccine coverage (e.g., health insurance status, income-to-poverty ratio, parental report of child’s influenza vaccination) can be compared to similar estimates from the NHIS overall and among landline only populations.

Simulation Procedure

To allow for the situation where input to the simulation model is in the form of a postulated bias (difference between vaccination rates in response vs. nonresponse groups), each run of the simulation will begin at the last stage of the survey process and work backwards. For example, a vaccination rate value will be drawn first for children with a completed interview but not having adequate provider data (μ_{7A}), and then a vaccination rate value for children with provider consent will be computed as a weighted average of rates for those with and without adequate provider data [$\mu_6 = p_7\mu_7 + (1–p_7)\mu_{7A}$]. Then, a vaccination rate value for children with completed interview but without consent (μ_{6A}) will be drawn and combined with the value for μ_6 to yield a value for μ_5. This process will continue up to the universe of eligible children, with a final value for μ computed.

The simulation will be run 1,000 times, or fewer if stable distributions are generated with fewer runs. For each run, estimates of overall bias will be computed using unweighted estimates ($\mu_7 – \mu$), as well as estimates of bias at each survey stage (e.g., $\mu_7 – \mu_{7A}$, $\mu_6 – \mu_{6A}$, $\mu_5 – \mu_{5A}$, $\mu_4 – \mu_{4A}$, $\mu_3 – \mu_{3A}$, $\mu_2 – \mu_{2A}$, $\mu_1 – \mu_{1A}$, $\mu_1 – \mu_{1B}$, $\mu_1 – \mu_{1C}$, $\mu_1 – \mu$). The extent to which the weighted estimate of μ_7 is closer to μ than the unweighted estimate also will be examined, and the final estimated bias in reported vaccination rates estimated by $\mu_{7(\text{weighted})} – \mu$. To assess the influence of nonresponse at different stages, we can widen the uncertainty in vaccination rate distribution for a given stage, using the “best” model distributions for other stages, and examine the resulting distribution of bias. Alternatively, we can use the “best” model distribution for a given stage and assume no bias in other stages.

DISCUSSION

Summary

We propose a framework for quantifying systematic error in a RDD survey that targets households with young children, identifies the children’s providers, and then surveys these providers to collect validated vaccination histories. The model includes noncoverage of the RDD frame and explicitly defines nonresponse groups at each stage of the survey process. We propose to conduct a variety of noncoverage and nonresponse bias assessment studies to provide input into the model. The model can be established before any of these studies are completed and re-run as new information is obtained. Monte Carlo simulation is proposed to quantify the uncertainty in model input parameters and to allow flexible assumptions about input probability distributions without having to derive joint probability distributions.

Strengths

A main strength of this approach is to explicitly define each of the survey stages where systematic error can arise. This can identify stages where relatively little information is available about vaccination rates in nonresponders and which stages are potentially most influential in introducing nonresponse bias. This approach also facilitates planning of studies to assess nonresponse bias. A variety of approaches have been proposed to assess nonresponse bias, each with its own limitations. The approach proposed here synthesizes information from these studies, and translates them into the main quantity of interest, the bias due to noncoverage and nonresponse. Potential uses of the model include identifying influential survey stages to target for reductions in nonresponse bias, modeling potential effects of specific efforts to improve response rates or reduce nonresponse bias (e.g., incentives), identifying survey stages for which additional information is critical in reducing variability in the simulated distribution of bias, aiding in interpretation of response rates and deciding how to report them, evaluating current weighting and adjustment approaches and modeling potential effects of potential improvements, and modeling of potential differential nonresponse by subgroups (e.g., race/ ethnicity, geographic area).

Limitations

Like any sensitivity analysis, findings will be determined in part by assumptions that must be made in the model structure and input parameters. In absence of direct estimates of vaccination rates in groups not covered by the sampling frame or who do not respond at various stages, findings from the sensitivity analysis cannot be absolutely definitive. In application to the NIS, we have a rich set of data to assess nonresponse related to the provider phase of the survey and less information on upstream stages of the RDD component. Particularly, there is little information available on eligibility rates among resolved and screened households and the extent to which screened eligible households fail to declare their eligibility. Even for assessment of bias at the provider phase of the survey, where we have household-reported information on factors associated with vaccine coverage, we must make assumptions that nonresponse is not related to vaccination coverage after controlling for these factors or postulate departures from these assumptions. The NHIS data can provide valuable information regarding potential noncoverage bias. The NHIS covers both telephone and nontelephone households in the survey. However, this analysis will be limited by available sample size for households with young children and must be repeated at least annually, given the steady increase in prevalence of wireless-only households. The NHIS data is itself subject to error from nonresponse and misclassification of household telephone status. Also, without provider-validated vaccination status available for NHIS respondents, we must rely on proxy measures available on NHIS or compute vaccination status using a model based on factors associated with coverage. In this paper, we did not incorporate information on geographic stratum in the model nor did we address potential bias in vaccination coverage among subgroups (e.g., by race/ethnicity). There may be variations in response rates at different stages and in eligibility rates by geographic stratum.

Next Steps

It is likely we will refine the model as we develop it for the NIS. Once implemented and revised as more information about potential nonresponse and noncoverage bias become available from proposed studies, its value can be reassessed. It may be that simpler approaches, such as benchmarking to the NHIS or other surveys, will provide adequate assessment of potential bias in future years of the survey. For example, questions on health insurance status were added starting with the 2006 NIS, and we are adding a question on parental report of influenza vaccination on the NIS starting in 2007, similar to a question currently on the NHIS. It is possible to incorporate measurement error and confounding into the model. For example, our current definition for having adequate provider data allows inclusion of children with multiple providers for whom not all identified providers responded, which likely results in underestimation of vaccination coverage to some extent. The NIS has been expanded to include an immunization survey of children age 13–17 years using the NIS sampling frame, including a provider record check phase. A similar sensitivity analysis model needs to be developed for this survey. Given rising prevalence of wireless-only households and declining response rates to RDD surveys, it is imperative that potential systematic error is quantified rigorously and periodically for RDD surveys. The proposed framework attempts to do this. Even if the sensitivity analysis yields a relatively wide distribution of potential bias, it is better to acknowledge this than to make implicit assumptions about lack of bias when reporting results or simply stating that residual bias of unknown direction and magnitude may remain after weighting adjustments.

REFERENCES

Battaglia, M. P., Khare, M., Frankel, M. R., Murray, M. C., Buckley, P., & Peritz, S. (in press). Response rates: How have they changed and where are they headed? In J. M. Lepkowski, N. C. Tucker, J. M. Brick, E. D. de Leeuw, L. Japec, P. J. Lavrakas, M. W. Link, & R. L. Sangster (Eds.), *Advances in telephone survey methodology*. New York: Wiley.

Blumberg, S. J., Luke, J. V., & Cynamon, M. L. (2006). Telephone coverage and health survey estimates: Evaluating the need for concern about wireless substitution. *American Journal of Public Health, 96,* 926–931.

de Leeuw, E., & de Heer, W. (2002). Trends in household survey nonresponse: A longitudinal and international comparison. In R. M. Groves, D. A. Dillman, J. L. Eltinge, & R. Little (Eds.), *Survey nonresponse.* New York: John Wiley & Sons.

Ezzati-Rice, T. M., Frankel, M. R., Hoaglin, D. C., Loft, J. D., Coronado, V. G., & Wright, R. A. (2000). An alternative measure of response rate in random-digit-dialing surveys that screen for eligible subpopulations. *Journal of Economic and Social Measurement, 26,* 99–109.

Graham, J. D. (2006, January 20). *Memorandum for the President's Management Council.* Executive Office of the President, Office of Management and Budget. Retrieved August 1, 2007, from www.whitehouse.gov/omb/inforeg/pmc_survey_guidance_2006.pdf

Greenland, S. (2005). Multiple-bias modeling for analysis of observational data. *Journal of the Royal Statistical Society A, 168,* 267–306.

Groves, R. M. (2006). Nonresponse rates and nonresponse bias in household surveys. *Public Opinion Quarterly, 70,* 646–675.

Groves, R. M., & Couper, M. P. (1998). *Nonresponse in household interview surveys.* New York: Wiley.

Hogan, H., & Wolter, K. M. (1988). Measuring accuracy in a post-enumeration survey. *Survey Methodology, 14,* 99–116.

Johnson, T. P., Cho, Y. I., Campbell, R. T., & Holbrook, A. L. (2006). Using community-level correlates to evaluate nonresponse effects in a telephone survey. *Public Opinion Quarterly, 70,* 704–719.

Lash, T. L. (2007). Heuristic thinking and inference from observational epidemiology. *Epidemiology, 18,* 67–72.

Lash, T. L., & Fink, A. K. (2003). Semi-automated sensitivity analysis to assess systematic errors in observational data. *Epidemiology, 14,* 451–458.

Link, M. W., Mokdad, A. H., Kulp, D., & Hyon A. (2006). Has the National Do Not Call Registry helped or hurt state-level response rates? A time series analysis. *Public Opinion Quarterly, 70,* 794–809.

Mulry, M. H., & Spencer, B. D. (1991). Total error in PES estimates of population. *Journal of the American Statistical Association, 86,* 839–863.

Phillips, C. V. (2003). Quantifying and reporting uncertainty from systematic errors. *Epidemiology, 14,* 459–466.

Salmon, D. A., Smith, P. J., Navar, A. M., Pan, W. K. Y., Omer, S. B., Singleton, J. A., et al. (2006). Measuring immunization coverage among preschool children: Past, present and future opportunities. *Epidemiologic Reviews, 28,* 27–40.

Skalland, B., Wolter, K., Shin, H. C., & Blumberg, S. J. (2006). *A nonresponse bias analysis to inform use of incentives in multistage RDD telephone surveys.* Paper presented at the 2006 Joint Statistical Meetings, Seattle.

Smith, P. J., Hoaglin, D. C., Battaglia, M. P., Khare, M., & Barker, L. E. (2005). *Statistical methodology of the National Immunization Survey: 1994–2002* (Vital and Health Statistics, Series 2, No. 138). Hyattsville, MD: National Center for Health Statistics.

Smith, P. J., Rao, J. N. K., Battaglia, M. P., Ezzati-Rice, T. M., Daniels, D., & Khare, M. (2001). *Compensating for provider nonresponse using response propensities to form adjustment cells: The National Immunization Survey* (Vital and Health Statistics, Series 2, No. 133). Hyattsville, MD: National Center for Health Statistics.

[Note]The findings and conclusions in this report are those of the authors and do not necessarily represent those of the

CDC.

FEATURE PAPER: Accommodating a Changing Panel Design

Darryl V. Creel, *RTI International*

INTRODUCTION

Panel surveys, in which the same sampling units are surveyed at different points in time, often are subject to a number of unique challenges. For instance, over time, analytical objectives of the research can change or evolve. In other situations, there can be changes with respect to availability of resources, funding, and data collection cost structure. All such changes can impact the panel survey design and the sampling units that are retained in the panel. Retention of the sampling units is particularly important because of the difficulty associated with recruiting sampling units and the benefits of continuity for variance estimation purposes. An example of changing survey objectives is when the analytical subdomains—e.g., geographic areas for which accurate estimates are required—expand, shrink, or shift. Consequently, it is possible for precision requirements of key survey estimates to increase or decrease. Changes in available resources, which include an increase in the cost of data collection and a reduction in funding, are rather obvious and more frequent.

In order to address these challenges, we describe Esbjorn Ohlsson's (1992, 1995, 1999) work on sample coordination based on the use of permanent random numbers that can readily adapt to changes in analytical objectives, resources, and data collection costs while maintaining many of the benefits of a panel survey design that lead to more accurate estimates of change over time. The advantage of this design is that it is easy to understand and implement. Specifically, while maintaining the probabilistic nature of each selection, this design allows the overlap between the two samples to be large. The flexibility of our proposed method provides a simple and efficient way to accommodate modifi-cations to the panel survey design that can occur over time. Consequently, data collection activities can proceed without any delay or loss of continuity for implementing *controlled selection*[Note 1] or some other method to address the emerging design changes. Additionally, the design introduces no further complications for sampling, weighting, variance estimation, or analysis for individual time periods or trends. That is, we reap the benefits of the design at virtually no cost, and the loss of efficiency due to changes in the panel survey design is small. Finally, we discuss some further research that could possibly extend Ohlsson's work to account for nonresponse.

This paper will illustrate the design methodology by using an example where sampling units, which are hospitals, are stratified by state, size of hospital, and ownership (i.e., public or private). The initial sample has proportional allocation with respect to the states and aims to produce accurate national estimates. The subsequent samples reflect any changes, if any, in the panel survey design. Also, the subsequent samples update the previous sample to account for new sampling units or newly eligible sampling units added to the population each year. The paper focuses on the implementation of the design and also discusses the design with respect to frame development, sampling, weighting, variance estimation, and analysis, including individual time periods and trends.

SURVEY DESIGN

The main features of this type of survey design are

1. It is a panel survey.
2. It incorporates permanent random numbers.
3. It can use stratification, simple random sampling, and/or probability proportional to size sampling.

Each of these features is discussed below.

The main reason for having a panel survey is that it can detect smaller differences between time periods than repeated cross-sectional surveys can.[Note 2] This is due to the fact that the sampling units are their own controls from one time period to the next. That is, the panel survey can measure the changes related to the same sampling units from one time period to the next. In general, multiple measurements on the same sampling unit are positively correlated, and there frequently is a high positive correlation. The panel design takes advantage of this and is able to produce smaller variances when testing differences from one period to the next, which, in turn, allows analysts to detect smaller differences that may go undetected when repeated cross-sectional surveys are used.

Repeated cross-sectional surveys use the same design from one time period to the next but collect information from independent samples in each period. Because of this, the independent samples contain an additional amount of variability; the more variability in the estimates, the more difficult it is to detect differences between time periods. The variance of a difference of two means for a panel survey and repeated cross-sectional surveys will be examined in the variance estimation section of this paper.

A permanent random number (PRN) is a unique and independent random number generated from uniform distribution on the interval (0,1). The PRN is generated for each sampling unit in the population and remains with the sampling unit as long as the sampling unit is on the frame (Ohlsson, 1992, 1995). The PRN allows us to have very large overlap between time periods of the panel survey.

Stratification partitions the frame into disjoint sets of sampling units with independent sampling within strata. It is an equal probability selection method within strata. Within a stratum, the sampling can be simple random sampling—i.e., each sampling unit has the same probability of selection—or probability proportional to size (PPS) sampling.

FRAME DEVELOPMENT

Frame development consists of the initial frame development and periodic frame updates.

Initial Frame Development

During the initial frame development, the normal frame development tasks (i.e., creating unique sampling unit identifiers, creating stratification variables, and eligibility determination) occur with the additional task of assigning PRNs to the sampling units on the frame.

Periodic Frame Updates

During any periodic update, a new sampling unit may be added to the frame or there may be some type of change related to sampling units already on the frame. A new sampling unit is referred to as a "birth," and the birth is assigned a PRN. We can check the PRN against the PRNs already on the frame and the other births to ensure it is unique. Conversely, when a sampling unit leaves the frame, referred to as a "death," its PRN is deleted with it (Ohlsson, 1992; 1995). Srinath and Carpenter mention a potential disadvantage to this approach to births: "…the PRNs of births [may not be] equally spaced on the interval [0,1]. This may lead to births being over- or underrepresented in the sample due to random chance" (1995, p. 174). To check for this problem, we can monitor the distribution of the PRNs for the births at each periodic frame update and cumulatively. Also, if the number of births is small, this should not be a problem.

Other types of changes (Struijs & Willeboordse, 1995) that may occur to sampling units already on the frame are a change in a particular characteristic of the sampling unit or a change of structure. Changes of structure include concentration, deconcentration, and restructuring.

SAMPLE ALLOCATION

The initial sample can use any of the standard procedures to optimally allocate the sample. In the subsequent samples, whether to reallocate the sample will depend on the complexity and magnitude of the changes to the survey design.

SAMPLE SELECTION

To select a simple random sample of size *n* sampling units from a population of size *N* without replacement in a stratum, we use a sequential simple random sampling without replacement method.

Method 4 in Fan, Muller, and Rezucha (1962) describes a two-stage sequential selection method to achieve this. In stage one, a uniform random number on the interval (0,1) is generated for each sampling unit. Assuming that these uniform random numbers are unique and independent, place the first *n* sampling units in a “reservoir.” For the remaining $N - n$ sampling units, if a sampling unit’s uniform random number is less than the largest uniform random number in the reservoir, include the sampling unit in the reservoir. Otherwise, ignore the sampling unit. For stage two, select the *n* sampling units in the reservoir with the smallest uniform random numbers. This provides a simple random sample without replacement of size *n*.

Ohlsson (1992, 1995) references the equal probability sampling JALES technique,[Note 3] which permanently associates the uniform random numbers to the sampling units creating PRNs. Using PRNs, Ohlsson (1992, 1995) describes a simpler sequential simple random sampling without replacement method. The sampling units are sorted by the PRNs, and the first *n* sampling units are selected for the sample. This provides a simple random sample without replacement of size *n*. Ohlsson (1992) provides a formal proof of this in Appendix 1.

To select a probability proportional to size sample of *n* sampling units from a population of *N* without replacement in a stratum, we will use a sequential random sampling technique recommended by Ohlsson (1999) based on Monte Carlo simulation. The technique is Pareto sampling, which was introduced by Rosen (1997). Pareto sampling is similar to sequential simple random sampling, but instead of sorting on the PRN alone, we sort on a function of the PRN, the measure of size, and the sample size in the stratum. The function for Pareto sampling is

$$\xi_i = \frac{X_i/(1 - X_i)}{np_i/(1 - np_i)},$$

where ξ_i is the value that will be sorted for the i^{th} sampling unit, X_i is the PRN for the i^{th}

sampling unit, n is the sample size in the stratum, and p_i is the normed measure of size for the i^{th} sampling unit, where the normed measure of size means that the sum of all of measures of size equals one. After sorting on the ξ_i, we select the first n sampling units.

WEIGHTING

For stratified simple random sampling, the design weight for a stratum is the inverse of the probability of selection for the sampling units selected into the sample and zero for the sampling units not selected into the sample. That is, the design weight for a stratum is the population size of the stratum divided by the sample size of the stratum for the sampling units selected for the sample and zero for the sampling units not selected for the sample. For stratified PPS sampling, the probability of selection is $1/np_i$, where n is the sample size for the stratum and p_i the measure of size for the i^{th} sampling unit, for sampling units selected into the sample and zero for the sampling units not selected into the sample. Any other weighting adjustments—e.g., nonresponse or poststratification—are conducted normally. Therefore, the design does not cause any complications when calculating the design weights or any other weighting adjustment.

VARIANCE ESTIMATION

Since we are using stratified sampling, we can easily use the same strata for estimating the variance. The variance is estimated using the standard formulas. As mentioned in the survey design section of the paper, to get an idea of the reduction in the variance estimates for the panel design versus a repeated cross-sectional design, we show the argument with the variance for the difference of two means.

Let t_1 be the mean for time period one and t_2 be the mean for time period two. Using simplifying assumptions that the variances for the means are equal for the two time periods, $S_1^2 = S_2^2 = S^2$, and that the sample sizes are equal for the two time periods, $n_{t1} = n_{t2} = n$, the variance for the difference of the two means for a repeated cross-sectional design is

$$\text{var}(t_2 - t_1) = \frac{2}{n} S^2.$$

Finally, let the correlation between the outcome variable at two time periods be r_{t1t2} and the amount of overlap between the two samples by l. The variance for the difference of two means for the panel design is

$\mathrm{var}(t_2 - t_1) = \frac{2}{n} S^2(1 - \mathrm{lr}_{t1t2})$.

Comparing the variance for the difference of two means for the repeated cross-sectional design and the variance for the difference of two means for the panel design, we see that the variance for the difference of two means for the panel design is smaller by a factor of $(1 - \mathrm{lr}_{t1t2})$. That is, the variance is reduced by the product of the amount of overlap between the two samples and the correlation between the outcome variable at two time periods.

ANALYSIS

There are two possible types of analysis. The first type is the independent analysis of the individual time periods, and the second type is the analysis of trends. The two most common types of trend analysis are comparing a time period with the initial, or base, time period and comparing two consecutive time periods.

Individual Time Periods

For the individual time periods, any software designed to analyze survey data, i.e., software that can account for the survey design and differential weighting, such as SUDAAN, can be used.

Trend Analysis

For the trend analysis, if the variable names on the two data sets have the same names, append —i.e., stack—one of the data sets to the other. Then any software designed to analyze survey data can be used. Each sampling unit will be considered a cluster for which there are two observations, one for each year.

EXAMPLE

Now that we have the basic idea, let us work through an example to solidify our understanding of the sampling and weighting. Suppose there is a proposed budget cut in the future, and we want to be prepared to cut back data collection to adhere to the proposed budget cut, if necessary. The example is a stratified sequential simple random sampling without replacement design with a decrease in sample size from the initial sample to the future sample and can be extended easily to Pareto sampling.

Table 1. Sample Allocation

Stratum	Population Size	Initial Sample Allocation	Future Sample Allocation
1	20	13	9
2	20	9	6
3	20	8	5
Total	60	30	20

Table 2. Selected Sampling Units for the Initial Sample & the Future Sample

		STRATUM 1				STRATUM 2				STRATUM 3	
ID	PRN	Initial Sample	Future Sample	ID	PRN	Initial Sample	Future Sample	ID	PRN	Initial Sample	Future Sample
17	0.124	1	***1***	8	0.053	1	***1***	3	0.006	1	1
4	0.156	1	***1***	11	0.096	1	1	11	0.021	1	***1***
8	0.182	1	1	1	0.223	1	***1***	4	0.040	1	1
15	0.189	1	***1***	18	0.253	1	***1***	16	0.140	1	1
10	0.341	1	1	10	0.282	1	1	15	0.447	1	1
1	0.350	1	1	17	0.461	1	1	20	0.578	**1**	***0***
18	0.416	1	1	14	0.463	**1**	0	14	0.601	**1**	0
13	0.429	1	***1***	3	0.492	**1**	***0***	6	0.602	**1**	0
7	0.430	1	1	9	0.497	**1**	0	7	0.608	0	0
6	0.480	**1**	***0***	20	0.506	0	0	17	0.711	0	0
3	0.491	**1**	0	7	0.602	0	0	5	0.714	0	0
19	0.516	**1**	***0***	19	0.701	0	***0***	8	0.723	0	0
11	0.600	**1**	0	4	0.703	0	0	13	0.802	0	***0***
12	0.675	0	0	2	0.805	0	0	2	0.844	0	0
2	0.684	0	***0***	6	0.877	0	0	1	0.846	0	0
20	0.702	0	***0***	12	0.910	0	0	10	0.875	0	***0***
16	0.706	0	0	13	0.935	0	0	9	0.943	0	0
9	0.775	0	***0***	5	0.938	0	0	19	0.962	0	***0***
14	0.779	0	0	16	0.939	0	***0***	18	0.978	0	0
5	0.887	0	0	15	0.978	0	0	12	0.986	0	0

For simplicity, assume we have three strata, each with a population of 20 sampling units; we have selected the initial sample using stratified simple random sampling without replacement using the sample allocation for sample one in Table 1; and we are in the data collection phase.

During the data collection phase, an unanticipated challenge arises. The data collection challenge could be a lack of available resources to collect data from all of the sampling units selected into the sample, a reduction in funding, or a change in the data collection cost structure where the cost for data collection per sampling unit is higher than expected. To adapt to the data collection challenge, we decide to implement the future sample designed for the proposed budget cut. The new sample size is smaller by one-third. We calculated the sample allocation for the future sample in Table 1. Table 1 contains the stratum, the population size, the initial sample allocation, and the future sample allocation.

For the initial sample, using the PRNs and the sequential selection method described in the sample selection section of the paper for each stratum, Table 2 shows the sampling units selected. Concisely, we generated a uniform random number on the interval (0,1) for each sampling unit, sorted the sampling units by the PRN, and selected the first n_h sampling units in stratum h, where n_h is given in Table 1. Table 2 contains the stratum, the ID of the sampling unit, the PRN, and the indicator variable for selection into the initial sample.

To reduce the sample size by one-third to adapt to our data collection challenge, we use the same sequential sample selection method used to select the sampling units in the initial sample and the future sample. The only difference is the change in the number of sampling units selected in stratum h, n_h. Table 2 also contains the indicator variable for selection into the future sample. The bolded ones, **1**, for the indicator variable for selection into the initial sample, are the sampling units that are dropped from data collection. For comparison, a simple random sample would contain the italicized sampling units in the future sample column. Note that the simple random sample does not have nearly as much overlap as the sequential simple random sample. This illustrates the considerable overlap provided by the sequential simple random sample methodology as compared to the simple random sample methodology.

Because we have two different sample sizes in each stratum, we need to have two different weights for each stratum: the initial sample design weight and the future sample design weight. The design weights by stratum for the two samples are shown in Table 3. In this example, we have a reduction in sample size from the initial sample to the future sample. Consequently, the design weights by stratum in the initial sample are less than the design weight by stratum in the future sample. In either case, the product of the stratum design weight and stratum sample size is equal to the stratum population size.

Table 3. Design Weights for Sample 1 & Sample 2

Stratum	Population Size	Sample 1 Allocation	Sample 2 Allocation	Sample 1 Design Weight	Sample 2 Design Weight
1	20	13	9	1.538	2.222
2	20	9	6	2.222	3.333

3	20	8	5	2.500	4.000
Total	60	30	20	-	-

CONCLUSION

The events described in this paper demonstrate the need to be prepared to adjust the panel survey design to meet some change, either planned or unplanned, in the requirements for the panel survey design. The design, which uses permanent random numbers in conjunction with stratified random sampling, is a relatively easy, flexible approach to implement these changes.

The flexibility of the design can be extended in two ways: allowing the stratification scheme to change and calculating sample size requirements at each time period. First, allowing the stratification scheme to change would allow for the incorporation of totally different strata. For example, if the current stratification scheme is based on state, perhaps the incorporation of Core-Based Statistical Areas (CBSAs) could be added to produce estimates at this level to meet new analytic objectives. Second, calculating sample size requirements at each time period would allow for better allocation of the sample. For example, using information about the size of the variance in strata could assist in producing optimal sample sizes. Finally, a combination of changing analytic objectives (e.g., adding CBSAs) and an accompanying increase in funding could be addressed and seamlessly incorporated into the next data collection period at virtually no additional cost while maintaining a very large overlap between the two samples.

One area for further research extends current work to account for which sampling units respond. Ohlsson's (1992, 1995, 1999) and Rosen's (1997) work provides significant overlap between samples but does not account for whether the sampling units responded. Retaining nonresponding hospitals from the initial sample and dropping responding hospitals would be extremely inefficient. We would like to retain as many of the responding sampling units as possible, particularly if these responding units are extremely important for any reason (e.g., analytic objectives). We are attempting to identify a function that incorporates the response propensity, measure of importance, or level of recruitment effort and retains these responding hospitals in a probabilistic manner. One other aspect we are considering in this research is the effect of the specific hospitals retained on the mean square error of the estimates from the survey data.

REFERENCES

Duncan, G., & Kalton, G. (1987). Issues of design and analysis of surveys across time. *International Statistical Review, 55,* 97–117.

Fan, C. T., Muller, M. E., & Rezucha, I. (1962). Development of sampling plans by using sequential (item by item) selection techniques and digital computers. *Journal of the American Statistical Association, 57,* 387–402.

Goodman, R., & Kish, L. (1950). Controlled selection—A technique in probability sampling. *Journal of the American Statistical Association, 45,* 350–372.

Kish, L. (1965). *Survey sampling*. New York: John Wiley & Sons.

Kish, L., & Scott, A. (1971). Retaining units after changing strata and probabilities. *Journal of the American Statistical Association, 66,* 461–470.

Keyfitz, N. (1951). Sampling with probabilities proportional to size: Adjustment for changes in the probabilities. *Journal of the American Statistical Association, 46*(235), 105–109.

Ohlsson, E. (1992). *SAMU: The system for co-ordination of samples from the Business Register at Statistics Sweden—A methodological description* (R&D Report 1992:18).Stockholm: Statistics Sweden.

Ohlsson, E. (1995). Coordination of samples using permanent random numbers. In B. G. Cox, D. A. Binder, B. N. Chinnappa, A. Christianson, M. J. Colledge, & P. S. Kott (Eds.), *Business survey methods* (pp. 153–169). New York: John Wiley & Sons.

Ohlsson, E. (1999). *Comparison of PRN [Permanent Random Number] techniques for small size PPS sample coordination* (Research Report No. 210). Stockholm, Sweden: Stockholm University, Institute of Actuarial Mathematics and Mathematical Statistics.

Rosen, B. (1997). On sampling with probability proportional to size. *Journal of Statistical Planning and Inference, 62,* 159–191.

Srinath, K. P., & Carpenter, R. (1995). Sampling methods for repeated surveys. In B. G. Cox, D. A. Binder, B. N. Chinnappa, A. Christianson, M. J. Colledge, & P. S. Kott (Eds.), *Business survey methods* (pp. 171–183). New York: John Wiley & Sons.

Struijs, P., & Willeboordse, A. (1995). Changes in populations of statistical units. In B. G. Cox, D. A. Binder, B. N. Chinnappa, A. Christianson, M. J. Colledge, & P. S. Kott (Eds.), *Business survey methods* (pp. 65–84). New York: John Wiley & Sons.

[Note 1]Controlled selection is “any process of selection in which, while maintaining the assigned probability for each unit, the probabilities of selection for some or all preferred combinations of *n* out of *N* units are larger than in stratified random sampling (and correspondingly the probabilities of selection for at least some non-preferred combinations are smaller than in stratified random sampling)” (Goodman & Kish, 1950, p. 351). The most common approach is described in Kish and Scott (1971), which extends the Keyfitz (1951) method.

[Note 2] Pp. 457–477 in Kish (1965) contain sections 12.4, *Correlations from Overlaps in Repeated Surveys*, and 12.5, *Panel Studies and Designs for Measuring Change*. These sections provide detailed explanations of the variance calculations for repeated cross-sectional, panel, and rotating panel designs. They also document the advantages of panel or rotating panel design with respect to gross change behind a net change between two years.

Duncan and Kalton (1987) provide an overview of the advantages and disadvantages of various designs of surveys across time.

[Note 3] “In the SAMU [the coordinated sample system at Statistics Sweden], samples are drawn by the so called JALES technique, developed at Statistics Sweden in the early 70's by Johan Atmer and Lars-Erik Sjöberg (for whom 'JALES' is an acronym)" (Ohlsson, 1992, p. 2). "The Swedish SAMU system uses sequential *srswor* with PRNs to coordinate sampling across surveys and over time" (Ohlsson, 1995, p. 155).

FEATURE PAPER: Survey Mode Choices: Data Quality and Costs

J. Michael Brick and Graham Kalton, *Westat*

INTRODUCTION

A key decision to be made early in planning a survey is the mode or modes of data collection to be used. This paper discusses the factors entering into this choice, with a focus on health surveys of persons and households (rather than establishments). In selecting a primary data collection mode, researchers generally must choose between face-to-face (f-to-f) interviewing, telephone interviewing, mail questionnaires, and Web-based data collection. In recent years, mixed-mode surveys have become increasingly attractive as a way to address the limitations of any single mode. Also, with face-to-face and telephone modes, there is a further choice to be made between interviewer- and computer-administered questions.

The choice of mode depends on costs and data quality considerations, and often trade-offs between the two. In some cases, the choice is made with little debate, but in others, it is less straightforward. In all cases, however, a complex combination of factors must be taken into account in making an informed choice. Costs and quality both have several dimensions. For example, costs associated with a given mode include not only data collection costs but also sampling and processing costs. Quality includes both data accuracy and timeliness, with accuracy depending on the errors introduced through the measurement process, sampling error, noncoverage, and nonresponse.

MODE ALTERNATIVES

Face-to-Face

In the f-to-f mode, an interviewer typically contacts the sampled unit and conducts the interview or data collection. Having an interviewer at the door has some significant advantages that are difficult to emulate completely in other modes. An interviewer's physical presence often results in higher response rates and provides the opportunity to implement other activities, such as making observations, collecting specimens (e.g., paint chips, biomarkers), reviewing records (e.g., immunization cards, prescriptions), helping the respondent understand the data collection requirements, and showing visual aids. Also, incentives can be delivered directly to sampled persons, providing a proximate stimulus to increase response. Finally, f-to-f interviewing has a distinct advantage over other modes when the interview is very long (e.g., more than an hour).

Paper-and-pencil (PAPI) methods were used routinely in f-to-f interviews until the 1990s, after which computer-assisted personal interviewing (CAPI) became the main method, especially for large health surveys. Computer administration has substantial benefits over PAPI in terms of data quality, complex navigation of the survey items, timeliness in processing, and availability of paradata (see Couper & Nicholls, 1998, for more on the benefits of computerized methods). Computer administration is now fairly standard in all modes, with the exception of mail surveys. PAPI methods are generally used with the f-to-f mode only for smaller or specialized surveys, which are outside the main scope of this review.

A major reason for introducing computer-assisted self-administered interviewing (CASI) methods in f-to-f surveys was to avoid the potentially biasing effects of having interviewers ask the questions and record the answers to sensitive items or topics with potentially high social desirability effects. A variant of this method, audio computer-assisted self-administered interviewing (ACASI), has the additional benefit of reducing dependence on the literacy of the respondents by presenting the questions over headphones.

The most serious disadvantages of the f-to-f mode are the cost of data collection and the time required to field and process a major survey. Some activities are more extensive and time-consuming than in other modes, including listing and sampling. The use of the U.S. Postal Service (USPS) Delivery Sequence File (DSF) as a sampling frame of residential addresses for the f-to-f mode would result in a reduction in the time (and costs) associated with some of these procedures. However, many questions about the DSF coverage rate are yet to be researched fully, including its coverage for subgroups such as rural areas, multiple dwelling units, and rapidly growing areas.

Telephone

Like the f-to-f mode, the telephone mode offers the advantages associated with having interviewers contact sampled units and conduct interviews. An additional advantage of this mode is the ability to monitor and assess the performance of the interview process directly during data collection. Technological advances in telephony make this monitoring possible even with decentralized telephone administration. Another potential advantage of the telephone mode is its suitability for addressing contact and interview problems with non-English-speaking respondents. If the instrument is translated into multiple languages, then hiring and training interviewers with the appropriate language skills is feasible with telephone surveys. F-to-f and other modes have greater obstacles in dealing with non-English-speaking persons. A distinctive feature of the telephone mode is the availability of a relatively comprehensive and inexpensive sampling frame of households based on phone numbers.

Computer-assisted methods were developed and first implemented for the telephone mode, specifically computer-assisted telephone interviewing (CATI). Almost all but the smallest surveys currently conducted by phone use CATI. A variant of this mode uses interactive voice response (IVR) technology. The main attraction of IVR is that it eliminates interviewers from the process, providing cost advantages and potentially improving the quality of responses to sensitive items. IVR can be used within a telephone interview to collect responses to sensitive items and then return the respondent to the interviewer. However, the use of IVR as the sole mode is unsuitable for most health surveys of the general population because its impersonal nature results in extremely low response rates.

The main disadvantages of the telephone mode are low response rates, especially in random-digit-dialing (RDD) surveys, and reliance on aural communication. Other disadvantages include inability to collect physical specimens and coverage problems in the RDD frame for landline telephones, primarily due to the increasing number of households that are relying only on cell phones. The effect on data quality of the use of IVR to collect responses on sensitive topics has not yet been tested sufficiently. Providing incentives with telephone surveys lacks the immediacy possible with f-to-f surveys and addresses for advance mailings.

Mail

Data collection costs are low with the mail mode because the questionnaire is self-administered. This mode also avoids possible interviewer effects. Mail data collection allows respondents to control the pace of response, enabling them to consult records or obtain data from another source if necessary. The visual presentation also gives respondents the opportunity to study the full set of response alternatives before answering and to view visual aids designed to assist comprehension. While mail surveys are still largely based on list frames, the feasibility of using the mail mode for the general household population has been enhanced by the availability of the DSF (however, see the issues discussed above regarding use of the DSF for f-to-f surveys).

The main disadvantages of this mode are consequences of the absence of an interviewer. Without an interviewer, methods for sampling a person within a household and persuading that person to respond are limited, and response rates may suffer. Dillman (2007) describes procedures in which multiple mailings are used to increase response rates, but such approaches may adversely affect the survey’s timeliness. Also, it is not possible to control who completes the questionnaire, which is a particular problem when responses are required from a specified, perhaps sampled, household member (Scott, 1961). The questionnaire must be simple enough for respondents to be able to navigate it, and its content must be suitable if people with low literacy levels are surveyed. Question ordering techniques cannot be used with the mail mode in the way they can be used with other modes because respondents can read all of the questions before starting to complete a mail questionnaire.

Web

Because Web surveys are self-administered, like mail questionnaires, Web-based data collection has low costs and eliminates interviewer effects. While the Web shares many of the benefits of the mail mode, it also has the advantages associated with computerized interviews, such as controlling complex skip patterns, making multimedia presentations possible, and allowing direct data entry. Another advantage of this mode is its timeliness.

The main disadvantages of this mode are the limited number of people with ready access to the Web, the absence of a sampling frame for the general population, and very low response rates. As with mail, it is difficult to control who actually completes a Web questionnaire. These serious disadvantages have thus far ruled out the use of the Web as the sole mode for health surveys of the general population.

Mixed Modes

By using two or more modes for data collection, survey researchers aim to take advantage of the various strengths of different modes in the same survey. One approach is to use the lowest cost mode that meets the survey requirements in the first stages of the survey, with more expensive modes used to deal with nonrespondents or those who could not be contacted by the other modes (as, for example, is done in the American Community Survey). Panel surveys also frequently use multiple modes, with f-to-f methods used in the initial wave and the less expensive mail, telephone, or Web modes used to the extent possible in subsequent waves.

In mixed-mode surveys, the potential for differential mode effects is a major concern—that is, responses to the same items may differ across modes. These effects may come about, in part, because of differences in the preferred designs of data collection instruments for the different modes. A unimode design that does not utilize the optimal features of the different modes has been suggested as a way to avoid this component of mode effects (see the appendix in Dillman, 2007). Evaluating mode effects is generally very difficult if the characteristics of sample persons differ across modes. This is often the case because the mode is "self-selected" when the person has not responded to earlier modes or when the information needed to interview the person (e.g., telephone number) by other modes is not available.

Based on a review of the literature on mode effects and mixed-mode designs, de Leeuw (1992,

2005) concluded that unambiguous, factual items generally have negligible mode effects, but that sensitive items and those involving social desirability often are reported differently in self- and interviewer-administered data collections. Mode effects typically result from the mixing of interviewer-mediated and self-administered modes or aural and visual modes. Mode effects are a major concern for panel surveys because estimates of change, a key analytic objective of such surveys, may be confounded with the effects of mixing modes across waves (Dillman & Christian, 2005).

COST & ERROR PROPERTIES

Cost

It is extremely difficult to compare data collection costs associated with different modes in a meaningful way. Groves (1989) discusses the difficulties and cites cost ratios for f-to-f to telephone surveys ranging from 1:1 to over 4:1 for the time at which he was writing. Even the 4:1 ratio is probably too low now, given changes in telephone data collection costs in the past two decades. One reason that direct comparisons are difficult is that the measurement process varies greatly by mode. Replicating the survey in another mode might not even be feasible. Furthermore, survey content often is tailored to utilize features of the chosen mode, and that content might not have been included with a different mode. For example, respondents might be asked to consult records on visits to medical providers in an f-to-f interview because it can be done easily and adds value, even if the record check is not essential to the goals of the survey. Similarly, respondents may be asked to consult records in self-administered modes. However, such requests are generally not made in telephone surveys because of the potential nonresponse and cost consequences.

The following are some general observations for relatively large household surveys:

- F-to-f is the most expensive mode, with data collection costs perhaps 5–10 times those of an equivalent telephone survey with the same number of respondents.
- Telephone is the second most expensive mode, with costs between 2–5 times higher than those of a mail survey with the same number of respondents.
- Mail is more expensive than the Web mode because of its higher processing costs, with the relative cost of mail to Web data collections rising as the number of respondents increases.
- Mixed-mode survey data collection costs typically include not only a weighted average of the data collection costs of each mode but also development costs (fixed costs) associated with each mode (which drive total costs higher).

In the f-to-f mode, the variable costs of field work are substantial and very different from the variable costs in other modes. For example, travel costs are not a component of any other mode. In f-to-f surveys, travel costs for training and for data collection are generally high. For health surveys that cover only a limited geographic area, these costs are much lower, thus making f-to-f surveys more competitive with telephone surveys from the cost perspective.

Although the telephone mode has many of the same sources of fixed costs as the f-to-f mode, the telephone mode fixed costs tend to be substantially lower. Variable costs are also substantially lower for telephone surveys than f-to-f surveys because interviewers have higher workloads, and there are usually no travel costs for training or data collection.

In contrast to the interviewer-administered modes, fixed costs account for a large proportion of the total cost for the mail and Web modes, even though these costs are substantially less than for the f-to-f and telephone modes. Mail surveys incur variable costs because of postal fees and processing of completed instruments. With the Web, most of the costs are fixed costs associated with the development of the Web application. Since variable costs are limited to any review and editing of the responses, the sample size is often not a concern with Web surveys. However, as noted earlier, there are other concerns that make the Web unacceptable as the only mode.

Mixed-mode surveys generally have higher fixed costs than might be expected, especially when the same computerized application cannot be used for all the modes. Most of these costs are the fixed costs associated with mounting the survey in the different modes. Also adding to the fixed costs for mixed-mode surveys are the special efforts that are needed to deal with features of the survey that otherwise might lead to mode differences.

Sampling Error

Sampling error and variable costs are highly correlated, but the fixed costs component makes the relationship of sampling error with total costs very nonlinear for some modes. Variable costs are also more closely related to sample size than to sampling error. Sampling error depends on the sample design as well as the sample size, and sample design may differ by mode. For example, most f-to-f surveys use cluster samples for efficiency, but clustering tends to increase sampling errors. Thus, comparisons of costs by mode should be based on equal effective sample sizes (the sample sizes divided by the design effects) rather than equal sample sizes. However, even this relationship is complex because the design effects for different survey estimates differ, thus producing different effective sample sizes for the comparisons.

In assessing sampling error requirements and mode choices, some important considerations are level of geographic detail needed (national, state, local), level of demographic or other domain detail needed, and the screening ratio (number of households screened to reach one eligible). The precision level requirements for the domain estimates or estimates of a rare population may have an enormous effect on the choice of the mode.

When a survey requires precise estimates, especially at smaller geographic levels and for domains or subgroups, then the expensive modes (such as f-to-f and, to a lesser extent, telephone) become less feasible. Although research on the use of the less expensive modes is underway, mail and Web surveys are not yet commonplace for most large-scale government health surveys. Other alternatives that may be considered include the following:

- Mixed modes—using the least expensive modes for screening and the more expensive modes for interviewing;
- Two-phase samples—using less expensive modes to collect data on a large sample, with a second-phase sample to obtain more detailed data for a subsample; and
- Small area estimation—using direct estimates for large geographic areas or domains and indirect (model-based) estimates for smaller domains.

Noncoverage Error

Coverage is more a function of the frame than the mode, but clearly the two are highly related. The high coverage of the population afforded by area probability samples with the f-to-f mode is one of its primary advantages. The coverage of the RDD frame was good through the 1990s, with the exception of very low-income households. Beginning earlier this decade, the percentage of households without a regular landline telephone began to increase, and by 2006, nearly 10% of adults lived in cell-phones-only households (Blumberg & Luke, 2007). Restricting a survey to households with landlines leads to a sizeable undercoverage. Efforts to sample cell phone numbers have begun, but more research is needed to evaluate their effectiveness.

Mail surveys traditionally have required special lists to cover the household population, and in this case the coverage rate depends on the quality of the specific list. The coverage properties of a list are related to its completeness and accuracy for the target population. Most lists have serious limitations for use as sampling frames. Lists obtained from administrative sources often are inaccurate and out of date. Another common problem is accessing the list, and new restrictions on the use of the Centers for Medicare and Medicaid Services (CMS) file of Medicare beneficiaries is a good example. The CMS no longer releases names and addresses to researchers to directly contact beneficiaries.

Although reasonable frames of the population exist for f-to-f and telephone surveys, there is no equivalent available for mail surveys. The USPS DSF mentioned earlier may provide a national frame for mail surveys if further research indicates it has an acceptable coverage rate. Even if its coverage rate is acceptable, the ability to randomly sample a person within a household and have the sampled person complete the questionnaire is a thorny problem that diminishes the utility of that frame.

As noted above, the coverage of the general population for Web surveys is poor, making the Web unattractive for all but special population surveys at the current time. Although access to the Web in either the person's home or at work has increased greatly in the past 15 years, it seems to have reached a plateau, with more than 30% of the population still uncovered (Pew Internet and American Life Project, 2006).

Even those people who have access to the Web cannot generally be sampled directly for Web surveys because there is no sampling frame for this population. An approach that has been used to deal with the lack of a Web frame is to sample using another frame/mode (e.g., by telephone) and enlist the sampled members to participate in a panel of Web surveys. If the sampled persons do not have Web access, then it must be provided to them or they remain uncovered. This approach is still being evaluated; however, it incurs coverage loss depending on the frame used to sample the households and errors from other sources, such as nonresponse (Huggins, Dennis, & Seryakova, 2002; Saris, 1998).

On its own, the Web mode is mainly used to survey specialized populations, such as college students. The Web mode also has been used for surveys of establishments such as medical providers rather than for household populations.

Nonresponse Error

Response rates vary substantially by the mode of contact and data collection. The typical pattern is that f-to-f surveys have the highest response rates, followed in order by telephone, mail, and Web surveys. The presence of interviewers is critical to the higher rates, especially in the f-to-f mode. In the f-to-f mode, other methods of increasing response, such as offering incentives, are easier to administer than in even the phone mode, where promised incentives have not been found to be very effective.

Other factors related to both the use of an interviewer and response rates may be important for some surveys. An interviewer can present information on the confidentiality of the data supplied by the respondent, respond to respondent queries about confidentiality, and convey the credibility of the sponsor in ways not possible in self-administered modes. An interviewer is also useful if release forms must be signed before interviews can be conducted (e.g., parent permissions for adolescents to be interviewed). All of these factors tend to benefit the interviewer-administered modes.

Dillman (2007) argues that mail surveys can overcome some of these obstacles and achieve better response rates if the surveys and the materials accompanying them are well-designed. He describes several experiments, mainly for special populations or subgroups, that demonstrate that good response rates can be achieved by mail. The experiments of Link and Mokdad (2006) add some support to this idea for a more general household population. However, a limitation in Link and Mokdad's most encouraging finding is that it compares response rates from mail surveys of nonrandomly sampled adults to response rates from telephone surveys of randomly sampled adults. More comparable evidence for the general population is needed.

Web surveys have fared poorly in terms of response rates in the few surveys that have used a probability sample from which response rates could be computed. Dillman (2007) suggests that while careful design may improve surveys on the Web, innovative approaches will be necessary to improve response rates.

Thus far, we have considered response rates but not nonresponse bias. This is largely because response rates are much easier to measure than nonresponse bias. Response rates often have been treated as surrogates for nonresponse bias, but the relationship between the two may be weak (Groves, 2006). For some estimates, factors such as sponsorship, survey topic, and accessibility for contact may be more predictive of nonresponse bias than the overall response rate. These factors may or may not be related to mode. The findings of Link and Mokdad (2006) suggest there is greater SES nonresponse bias in general population mail surveys than in phone surveys with comparable response rates. In the absence of a body of evidence, we suspect that most researchers would rank nonresponse bias as lowest in f-to-f surveys, followed by the telephone, mail, and Web modes. This ranking matches the response rate rankings by mode stated earlier, even though response rates may be poor predictors of bias.

The nonresponse bias in a survey's estimates may be reduced by weighting adjustments. However, the effectiveness of these adjustments in reducing bias is also not well-documented. If nonresponse is correlated with factors such as income, then weighting adjustments in f-to-f surveys may have greater potential to reduce nonresponse bias because features of the area and interviewer observations of the sampled unit can be linked to the sampled units easily. RDD surveys can obtain only aggregate exchange/ZIP code-level data for the adjustments, and they may be incorrect due to matching problems. In practice the effectiveness of nonresponse weighting adjustments is rarely considered in choosing a mode.

Measurement Error

Across a wide range of mode research, the largest and most consistent mode effect that has been observed is what de Leeuw (1992) calls the interviewer effect. Her literature review found that respondents in interviewer-administered surveys give more socially desirable responses than respondents in self-administered surveys. Most of the literature has compared interviewer-administered f-to-f or telephone surveys to self-administered mail surveys, with the effect having been traditionally interpreted as a mode effect. However, with the effect also occurring with the use of CASI in f-to-f surveys, it is now more appropriately associated with the interviewer than the mode.

Aquilino (1994) conducted an experiment to separate the mode effect from the interviewer effect in a drug and alcohol use survey. He found slightly lower reported usage by phone than f-to-f when both were interviewer administered. However, much larger differences were found between self- and interviewer-administered f-to-f interviews. Tourangeau, Rips, and Rasinski (2000) reviewed other experiments that show inconsistent results on the difference between modes when the interviewer effect is held constant. In summary, measurement errors in surveys with sensitive topics may be substantial unless the items are self-administered; CASI, ACASI, or IVR may be necessary to control measurement errors for f-to-f and telephone surveys that include sensitive topics.

While interviewer administration can be problematic in surveys about sensitive topics unless the proper precautions are taken, not having an f-to-f interviewer may make accurate measurements very difficult in other circumstances. For example, physical measurements of height and weight are much more accurate than respondent self-reports. Because interviewers are not present in person, the telephone, mail, and Web modes are not well-suited for surveys requiring physical measurements.

The other major source of mode differences is related to the method of question presentation: visual (ACASI, mail, Web) vs. aural (CAPI, phone). Redline and Dillman (2002) show that visual design and layout can greatly affect responses. Tourangeau et al. (2000) discuss how acquiescence, primacy, and recency differences might be related to the visual or aural presentation method. Because of its power, visual presentation has the potential to reduce measurement errors by focusing respondents appropriately. For example, respondents may more easily be able to choose one or more items from a long list when the information is presented visually. On the other hand, poorly designed layouts may have the opposite effect and increase measurement errors. We know of no meaningful rankings of measurement errors by presentation mode.

CONCLUDING REMARKS

Many factors are considered in deciding which mode or modes are most appropriate for a survey. Every choice involves balancing advantages and disadvantages associated with the modes. In most national surveys of the household population, the main alternatives are still the f-to-f and telephone modes. There are several important advantages of the f-to-f mode, especially in health surveys that require physical measurements, lengthy interviews, or the establishment of a relationship that will support later data collection, such as in longitudinal surveys. On the other hand, the f-to-f mode is much more expensive than the other modes.

If the funds for conducting the survey are limited or direct estimates for small subgroups or geographic domains are required, then f-to-f interviewing may have to be ruled out. A telephone survey may be the only viable option. Mail surveys are becoming more attractive as response rates and coverage rates fall in telephone surveys. A new round of research is needed to evaluate samples from the USPS DSF with respect to the many nonresponse, noncoverage, and control problems discussed earlier.

While the Web is not generally acceptable as the single mode in a survey, it is a prominent option that may be considered in surveys using mixed modes. Whether it is a cost-effective option depends on the extent to which respondents use it. Mixed-mode surveys can be designed to utilize the strengths of the various modes, but mode effects may be a serious problem and costs may be higher than budgets in some cases.

In the design stage, costs and sampling errors are important considerations that are easily estimated based on extensive past experience. Nonresponse and noncoverage are other important considerations affecting the mode choice. However, it is disconcerting when these rates are the main consideration. The focus on rates rather than biases may be due to our inability to measure or predict nonsampling errors quantitatively. Decisions on mode choice and other survey design features would be improved if acceptable ways could be found to assess quality in terms of errors rather than operational features such as response rates. Such quality measures would also help analysts to compare the quality associated with surveys having different sample sizes, coverage rates, and response rates.

REFERENCES

Aquilino, W. S. (1994). Interview mode effects in surveys of drug and alcohol use: A field experiment. *Public Opinion Quarterly, 58,* 210–240.

Blumberg, S. J., & Luke, J. V. (2007). *Wireless substitution: Preliminary data from the January–June 2006 National Health Interview Survey*. Retrieved July 19, 2007, from www.cdc.gov/nchs/products/pubs/pubd/hestats/wireless2006/wireless2006.htm

Couper, M. P., & Nicholls, W. L., II. (1998). The history and development of computer assisted survey information collection methods. In M. P. Couper, R. P. Baker, J. Bethlehem, C. Z. F. Clark, J. Martin, W. L. Nicholls II, & J. M. O'Reilly (Eds.), *Computer assisted survey information collection* (pp. 1–22). New York: Wiley.

de Leeuw, E. D. (1992). *Data quality in mail, telephone, and face to face surveys*. Amsterdam: TT Publications.

de Leeuw, E. D. (2005). To mix or not to mix: Data collection modes in surveys. *Journal of Official Statistics, 21,* 233–255.

Dillman, D. A. (2007). *Mail and Internet surveys: The tailored design method* (2nd ed.). New York: Wiley.

Dillman, D. A., & Christian, L. M. (2005). Survey mode as a source of instability in responses across surveys. *Field Methods, 17,* 30–52.

Groves, R. M. (1989). *Survey errors and survey costs: Probing the causes of nonresponse and efforts to reduce nonresponse*. New York: Wiley.

Groves, R. M. (2006). Nonresponse rates and nonresponse error in household surveys. *Public Opinion Quarterly, 70,* 646–675.

Hochstim, J. (1967). A critical comparison of three strategies of collecting data from households. *Journal of the American Statistical Association, 62,* 976–989.

Huggins, V., Dennis, M., & Seryakova, K. (2002). An evaluation of nonresponse bias in Internet surveys conducted using the Knowledge Networks Panel. In *Proceedings of the Survey Research Methods Section of the American Statistical Association* (pp. 1525–1530). Alexandria, VA: American Statistical Association.

Link, M. W., & Mokdad, A. (2006). Can Web and mail survey modes improve participation in an RDD-based national health surveillance? *Journal of Official Statistics, 22,* 293–312.

Pew Internet and American Life Project. (2006). *Percentage of U.S. adults online.* Retrieved July 18, 2007, from www.pewinternet.org/trends/Internet_Adoption_4.26.06.pdf

Redline, C., & Dillman, D. A. (2002). The influence of alternative visual designs on respondents' performance with branching instructions in self-administered questionnaires. In R. M. Groves, D. A. Dillman, J. L. Eltinge, & R. J. A. Little (Eds.), *Survey nonresponse* (pp. 179–195). New York: Wiley.

Saris, W. E. (1998). Ten years of interviewing without interviewers: The telepanel. In M. P. Couper, R. P. Baker, J. Bethlehem, C. Z. F. Clark, J. Martin, W. L. Nicholls II, & J. M. O'Reilly (Eds.), *Computer assisted survey information collection* (pp. 409–429). New York: Wiley.

Scott, C. (1961). Research on mail surveys. *Journal of the Royal Statistical Society. Series A (General), 124,* 143–205.

Tourangeau, R., Rips, L. J., & Rasinski, K. (2000). *The psychology of survey response*. New York: Cambridge University Press.

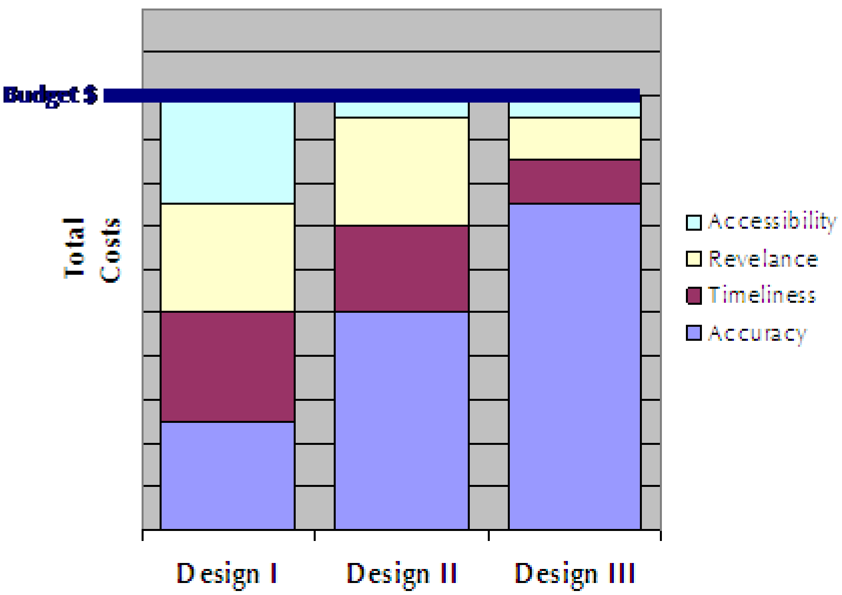
SESSION 5 DISCUSSION PAPER

Paul P. Biemer, *RTI International* and *University of North Carolina at Chapel Hill*

INTRODUCTION

The title of this session—*Trade-offs in Health Survey Design*—very well describes the general theme of all the six papers presented here. All the papers demonstrate, albeit in disparate ways, how various trade-offs enter into virtually every decision made in survey design, implementation, and data analysis. These trade-offs not only result from the tension between survey costs and quality, but also from the interplay among the various dimensions of survey quality.

Figure 1. Three Cost-Equivalent Designs



To many data users, accuracy is not synonymous with survey quality. To them, high quality is the result of properly balancing the various quality dimensions to suit their own specific needs. In the mid-1990s, government statistical agencies began to develop definitions of survey quality that explicitly regarded the multidimensionality of the concept (see, for example, Fellegi, 1996). These definitions gave rise to what has been referred to as a "survey quality framework." As an example, the quality framework used by Statistics Canada includes the seven quality dimensions: relevance, accuracy, timeliness, accessibility, interpretability, and coherence. Formal accepted definitions of these concepts can be found at the Web site of Statistics Canada (2006). The key notion here is that accuracy recedes somewhat in importance as other user-defined dimensions of quality are explicitly acknowledged.

To illustrate the trade-offs that arise in considering these dimensions, Figure 1 shows three cost-equivalent survey designs, each having a different mix of four essential dimensions of quality: accuracy, relevance, timeliness, and accessibility. In this figure, Design III seems to emphasize data accuracy while Design I is more balanced regarding all four quality dimensions. Determining the best design depends on the purpose of the survey and how the data ultimately will be used. All three designs have strengths and weaknesses, but the best design is the one having the most appropriate mix of quality attributes for its primary use. In that sense, all designs are optimal by some criteria and suboptimal by others.

Traditionally, optimal survey design has meant minimizing the total survey error subject to the cost constraints (see, for example, Groves, 1989). A survey model that brings together all the dimensions of quality into a single indicator, which would be ideal for survey design optimization purposes, does not exist. Instead, Biemer and Lyberg (2003) advocate an approach that focuses on accuracy while treating the other quality dimensions as well as costs as constraints to be met as accuracy is maximized.

As an example, if the appropriate balance of the quality dimensions is depicted by Design II in Figure 1, then the optimal survey design is one that maximizes data accuracy within that part of the survey budget allocated to achieving high data accuracy. In the case of Design II, the budget available for optimizing accuracy is approximately 50% of the total survey budget. Therefore, the optimal design will maximize data accuracy within this budget allocation while still fully satisfying the requirements of the other quality dimensions.

TRADE-OFFS FOR MAXIMIZING ACCURARY UNDER CONSTRAINTS

Once an appropriate budget has been determined for maximizing survey accuracy, the trade-offs begin to multiply as the design decisions increase in number. One decision that must be addressed early in the optimization of data accuracy is "Accuracy of what?" Accuracy varies by the survey variables and their associated statistics. In addition, different uses of the data demand different levels of accuracy, which introduces additional trade-offs among the survey's objectives. Balancing the various sources of error—sampling error, nonresponse bias, frame bias, questionnaire validity, interviewer error, data processing error, etc.—also involves numerous trade-offs.

In the end, however, a design that is truly optimal is really unachievable since, except in rare cases, too little is known about (a) the magnitudes of the errors by error source, (b) how they are altered by the various design decisions, and (c) how the errors interact in such a way that reductions in one type of error may lead to unintended increases in other types of errors. Faced with this complexity, survey designers will often resort to "design by intuition" rather than relying on MSE optimization models. One recurring theme among the papers in this session is the departure from the intuitive design approach in favor of the innovative use of statistical models and design methodologies that are informed by operational data.

PAPERS IN THIS SESSION

This session provides an excellent collection of papers with many interesting issues that can serve as excellent fodder for any discussant. The papers I have been asked to comment on include the following:

- *Responsive Design in a Continuous Survey: Designing for the Trade-off of Standard Errors, Response Rates, and Costs*—Groves, Lepkowski, Mosher, Wagner, and Kirgis
- *Design Trade-offs for the National Health and Nutrition Examination Survey*—Curtin and Mohadjer
- *A Simulation Model as the Framework for Quantifying Systematic Error in a Health Survey*—Singleton, Smith, Zhao, Khare, and Wolter
- *Changing Panel Design over Time*—Creel
- *Survey Mode Choices: Data Quality and Costs*—Brick and Kalton

The limited time available prevents me from discussing all of these papers. Instead, I will focus my discussion on a few papers that, in my opinion, present somewhat controversial issues, beginning with the fist paper by Groves et al.

The focus of paper by Groves et al. is on the control of nonresponse bias. The paper suggests that a survey manager's ability to reduce nonresponse bias depends on their ability to determine when the "capacity" of a particular phase of data collection has been reached. The capacity of a phase is the point at which response propensities of newly obtained respondents is on average approximately the same as previously obtained respondents. At this point, nonresponse bias is no longer being reduced, and it may be time to change data collection strategies in order to reach a different group of nonrespondents. In this manner, nonresponse bias in more effectively reduced, according to the authors.

As the authors point out, one's ability to predict response propensities is limited by the available process (or *para*-) data being collected for the current phase. Indeed, the authors have not yet been successful at identifying good predictors at each phase. However, even if good prediction models were available, the success of the responsive design approach also depends upon the ability of the field director to switch to a different data collection methodology, one that will substantially increase the response propensities for prior phase nonrespondents. This can be very difficult. Indeed, a methodology that may achieve success for increased response propensities may have unintended consequences for other error sources.

As an example, one approach advocated by Groves and Herringa (2006) is double sampling for nonresponse. With this approach, a subsample (say, 50%) of nonrespondents is selected and followed up more intensively by more proficient interviewers working under improved protocols (e.g., offers much greater incentives or better motivating arguments for nonrespondents to participate). There are important trade-offs with this approach. The primary trade-off is greater sampling variance in exchange for smaller nonresponse bias. The increase in sampling variance arises as a result of increased weight variation due to the weight adjustments that are inherent in the double sampling approach.

For example, Singh, Iannacchione, and Dever (2003) used a double sampling plan in the Gulf War Veterans Health Survey (GWHS). The sample size for the survey was 6,000 cases, and the response rate to the main survey was only 50%. After following up a 20% subsample of the nonrespondents, the weighted response rate increased to 78%. However, due to the increase in weight variation from double sample weighting, the effective sample size dropped from 1,672 to only 535 cases. Overall accuracy decreased as a result of double sampling even though nonresponse rate was substantially reduced. Singh et al. proposed an approach to contain the weight variation using calibration weighting, but they were unable to eliminate the problem.

For panel surveys, there may be other unintended consequences of the double sampling approach. For example, the effect of intensive follow-up efforts in early waves on response propensity in subsequent waves has not been studied. In addition to the bias-variance trade-off, panel surveys also may face the trade-off a higher response rate now in exchange for a potentially lower level of cooperation later. I encourage the authors to acknowledged and consider these issues in the paper.

Jumping now to the third paper, Singleton, Smith, Zhao, Khare, and Wolter provide another interesting case study in trade-offs for survey design. To illustrate the key ideas, suppose the bias due to nonresponse arises from two stages: screening and interviewing. The authors actually considered more than two stages, but this simple setup is sufficient illustration purposes. An expression for the bias due to nonresponse can be written as

$$B_{NR} = P_{NR}(\mu_R - \mu_{NR})$$

$$= P_{NR[1]}(\mu_R - \mu_{NR[1]}) + P_{NR[2]}(\mu_R - \mu_{NR[2]})$$

where μ_R is the mean of the respondents, $\mu_{NR[1]}$ is the mean of the screening nonrespondents and $\mu_{NR[2]}$ is the mean of the screening respondents who ultimately became interview nonrespondents in the second stage. Likewise, $P_{NR[1]}$ and $P_{NR[2]}$ are the screening nonresponse rate and the conditional interview nonresponse rate (i.e., given response to the screener). With this basic setup, the authors ask “How should resources be allocated to minimize B_{NR}?” For example, if one had to choose, would it be better to reduce $P_{NR[1]}$ or to reduce $P_{NR[2]}$? Likewise, if one had to choose, should attempts be made to reduce $(\mu_R - \mu_{NR[1]})$ or $(\mu_R - \mu_{NR[2]})$ in data collection?

To answer this question, the authors attempt to estimate the bias components in order to develop a strategy that minimizes the bias within the constraints of the survey design. However, a critical issue neglected in their framework is costs. For example, it might be much cheaper to reduce the bias arising from the first stage of data collection than from the second stage. Therefore, per unit of cost, it is possible that greater bias reduction could be achieved by investing survey resources to reduce the first-stage bias component even though it may be the smaller of the two components.

Clearly the authors propose a very innovative approach to an extremely important problem in data collection. We look forward to hearing more about the viability of this approach at future meetings.

Finally, I want to say just a few words about the paper by Brick and Kalton. First, their paper provides an excellent summary of the issues and trade-offs in the selection of the data collection mode(s). It is a very good review of the literature. However, one quibble I have with their paper regards the somewhat ambiguous use of the term “mode effect.” What is that? Its meaning is not really clear, and it tends to change according to the context. To illustrate this ambiguity, consider two survey modes referred to as Mode A and Mode B. Let y_{Ai} denote the ith observation collected by Mode A and let y_{Bi} be defined analogously for Mode B. Assume the following models hold for y_{Ai} and y_{Bi}:

$$y_{Ai} = \mu_i + b_A + e_{Ai}$$

$$y_{Bi} = \mu_i + b_B + e_{Bi}$$

Here μ_i is the true value for the ith unit, b_A and b_B are the mode biases terms, and e_{Ai} and e_{Bi} are error terms.

Even within this very simple framework, there are at least four ways to define the “mode effect.” For example, it can be defined as b_A and b_B, or the difference, b_A - b_B. It can also be defined as $E(y_{Ai} - y_{Bi})^2$, which only includes the errors of observation, or $E(\bar{y}_{Ai} - \bar{y}_{Bi})^2$, which includes the errors of observation and nonobservation. There may be other definitions that make sense in various situations.

How it is defined is critical to its interpretation in any given context. As an example, consider two surveys of the same population, each using a single mode—i.e., one uses Mode A alone and the other uses Mode B alone. In this situation, defining the mode effects as either $E(y_{Ai} - y_{Bi})^2$ or $E(\bar{y}_{Ai} - \bar{y}_{Bi})^2$ seems appropriate since the populations for each survey are identical. However, suppose instead one wishes to estimate the mode effect for a single mixed-mode survey that uses

Mode A initially and then switches to Mode B to follow the Mode A nonrespondents (e.g., mail with telephone follow-up). In this situation, the populations receiving each mode differ, and it is no longer appropriate to define the mode effect as $E(y_{Ai} - y_{Bi})^2$ or $E(\bar{y}_{Ai} - \bar{y}_{Bi})^2$. Instead, it may be more appropriate to think of the mode effect in terms of b_A and b_B. Further, the estimation of mode effects for mixed-mode surveys is quite challenging, much more so than in the case of two parallel surveys.

I think the authors of this paper would do the field a great service if these issues were discussed and the various definitions of the mode effect were clarified in their paper.

FINAL REMARKS

The papers in this session were excellent, and it was a privilege to be asked to comment on them. Collectively, they illustrate very well the many types of decisions and trade-offs involved in survey design. While truly "optimal" survey design is beyond our reach, it is possible to achieve near-optimal designs if one chooses wisely among the many trade-offs. Too often our design choices are uninformed and based more on intuition than data. The papers in this session provide a number of better alternatives to *design by intuition*. The methods they suggest are statistically rigorous, substantively informative, and, for the most part, operationally feasible. I look forward to hearing more from these authors about their methods as they further develop their ideas in future applications and presentations.

REFERENCES

Biemer, P., & Lyberg, L. (2003). *Introduction to survey quality.* Hoboken, NJ: John Wiley & Sons.

Fellegi, I. (1996). Characteristics of an effective statistical system. *International Statistical Review, 64*(2), 165–187.

Groves, R. (1989). *Survey errors and survey costs.* New York: John Wiley & Sons.

Groves, R., & Herringa, S. (2006). Responsive design for household surveys: Tools for actively controlling survey errors and costs. *Journal of the Royal Statistical Society, Series A, 169,* Part 3, 439–457.

Singh, A., Iannacchione, V., & Dever, J. (2003). Efficient estimation for surveys with nonresponse follow-up using dual-frame calibration. In *Proceedings of the ASA Survey Research Methods Section* (pp. 3919–3930). Alexandria, VA: American Statistical Association.

Statistics Canada. (2006). *Quality*. Retrieved June 19, 2007, from www.statcan.ca/english/edu/power/ch3/quality/quality.htm

SESSION 5 DISCUSSION PAPER

Reg Baker, *Market Strategies, Inc.*

Taken as a group, the five papers in this session might be viewed as the product of or perhaps a response to five interrelated trends that have been playing out over about the last 20 years. The most obvious of these trends is declining survey response rates and its immediate consequence of rising survey costs. Jon Krosnick has given us an especially compelling statement of the problem:

> *In the 1970s, you could get a telephone survey response rate of 70 percent. Now, if you work really hard, you might get 40 percent. Surveys on the front pages of major newspapers have response rates of 10 percent....It is still possible to conduct high-quality surveys—face-to-face interviews that yield 80 percent response rates—but such methods cost as much as $1,000 per subject....The question is, how do we get out of this mess?* (Trei, 2006)

The evidence is all around us and in all sectors of the survey research industry. For example, since 1996, the government's flagship health survey, the NHIS, has been losing about one point per year in its household response rate (C. Landman, U.S. Bureau of the Census, internal memorandum, 2005). Over roughly that same period, the University of Michigan's Survey of Consumer Attitudes has been losing about 1.5 points of response rate per year (Curtin, Presser, & Singer, 2005) and now struggles to achieve 50%. In commercial market research, single-digit response rates for RDD surveys are not uncommon. These trends are driven in part by public indifference—if not outright hostility—to surveys (increasing refusal rates), in part by the increasingly widespread use of defensive technologies such as answering machines and caller ID, and in part by changing lifestyle patterns that make it more difficult to find people at home to be interviewed (increasing noncontact rates). Reversing these trends is probably impossible. Spending more money on surveys will surely help, but that money is increasingly difficult to come by. A difficult mess, indeed, and one that all five of these papers attempt to address in one way or another.

The second trend is a redefinition of quality. Twenty or more years ago, the term "quality" might best be described using a manufacturing definition such as "free of defects" or "meeting all specifications." Translated to the language of survey research, this came to mean a high response rate from a well-designed probability sample. Deming launched a revolution when he redefined quality in the terms of the consumer rather than the producer. "The consumer," he wrote in *Out of the Crisis* (1982), "is the most important part of the production line." Juran (1992) further elaborated this concept when he coined the term "fitness for use" and argued that any definition of quality must include discussion of how a product will be used, who will use it, how must it will cost to produce it, and how much it will cost to use it. O'Muircheartaigh (1997) applied this "fitness for use" concept to survey research when he wrote that "...the concept of quality, and indeed the concept of error, can only be defined satisfactorily in the same context as that in which the work is conducted...to the extent that the context varies, and the objectives vary, the meaning of error will also vary…." Simply put, he argued that the data user is the ultimate arbiter of survey data quality, that as long as the data serve the purpose for which they were collected, then we can give less weight to absolutes, such as a high response rate. We have seen multiple examples of this principle at this conference, where, for example, data collections around disasters have provided invaluable information about the situation on the ground and about potential long-term health effects despite modest response rates. In this session, the Curtin paper is especially focused on design choices that may serve the needs of some data users better than others.

The third trend is a new perspective on the response rate itself. A special 2006 volume of *Public Opinion Quarterly* summarizing recent methodological research on nonresponse makes a convincing argument that understanding and controlling nonresponse bias may be as important if not more important than a high response rate. Some, like Groves (2006), have gone so far as to argue that traditional response rate enhancers (e.g., fostering topic saliency or incentives) may be counterproductive by virtue of the bias they create in who responds and who does not. Keeter (2006) has shown that at least where political attitudes and behaviors are concerned, there are few differences in estimates derived from a survey with a response rate of 50% on the one hand versus a survey with a response rate 25% on the other. Research by Holbrook and colleagues (in press) showed similar results for demographic distributions across a wide range of response rates, from as little as 4% to as high as 70%. Of course, much depends on the survey topic and the purpose for which the data are collected, but the research is increasingly convincing that a high response rate is no longer the requirement it once was.

Increased interest in mixed mode is a fourth trend. Historically, survey researchers mostly have looked to use different modes as a way to reduce costs. One often-used approach has been a mix of mail and telephone. The survey begins as a mail survey and then nonresponders are followed up by phone. More recently, we have begun to offer multiple modes as a way to improve response rates, believing that respondents sometimes have preferred modes in which they will respond and others in which they will not (see, for example, Link & Mokdad, 2004). But as Brick has described in his paper in this session, this is something of a slippery slope. We don't know as much as we need to know about the mode effects or response bias associated with different modes. We can identify these effects in our methodological studies but thus far have had difficulty measuring them and adjusting for them in the context of real surveys. Too often in the survey production setting the impact of mode differences goes without comment.

The final trend is the full adoption of CASIC. Automation of the survey process was promoted with a mantra of "better, faster, cheaper." But as Groves noted in his paper, one extremely valuable byproduct of CASIC adoption has been the generation of large amounts of data about the data collection process. Couper (1998) has called these data *paradata*. Scheuren (2001) further refined this concept by distinguishing two types of paradata. The first is *macro paradata,* which he describes as "global process summaries like overall response rate and coverage rates." These are traditional survey quality measures that CASIC now makes available to us in real time. The second type—*micro paradata*—refers to "detail known on each case." CASIC systems make it possible to analyze individual response data during data collection and, for example, to look at how well questions are working , to get a picture of whether the survey is yielding the data needed to study the problem at hand, or to identify any obvious response bias, such as demographic or strata imbalances. Extracting full value from these paradata requires that we have what Scheuren calls "listening systems" that allow both survey practitioners and their clients to assess nonsampling error in real time so that we can take corrective action. Scheuren further posits that survey design, development, and execution is a collaborative process between data collectors and data users. Or to paraphrase Deming, the data user is the most important player on the survey design team.

SUMMARY

As noted at the outset, these five trends form much of the context within which we now design and conduct surveys. The papers in this session reflect much of the current thinking about how survey design will need to change and adapt to the challenges we now face. I would summarize that thinking by suggesting that there are four things we need to do.

First, we need to start thinking of survey design as fluid rather than fixed. We should continue to design the best surveys we can, but we also need to be prepared to modify that design to deal with the reality in the field as we proceed through data collection. We should not just be alert to the possibility of redesign; rather, we should plan for it. Groves has described responsive design as one approach; Creel has offered PSAD as another.

Second, we very much need to develop some new metrics that reflect changing views of survey quality, metrics that operationalize our ideas about survey error. As Brick points out, we can say that nonresponse bias is more important than response rate, but it is terribly difficult to measure with any degree of precision. Similarly, we know there are mode effects, but we know little about how to measure and adjust for them.

Third, we need CASIC systems that collect and deliver these metrics. The basic work of automating the survey process is pretty much done. The new mission of CASIC ought to be to design the listening systems described by Scheuren, systems that not only produce the needed paradata but also give users the tools to analyze them.

Finally, and perhaps most importantly, we need to recognize that decisions about design must not only take the needs of data users into account but that users much be active participants in those decisions. As O'Muircheartaigh has said, survey data quality is defined "in terms of the aims and frame of reference of the researcher." The ultimate test is whether the survey data can effectively serve the purpose for which the data collection was commissioned. As survey designers and practitioners, we have a responsibility to provide the best and most timely information and recommendations we can manage, but decisions about quality and usefulness of survey data should rest ultimately with the data user.

REFERENCES

Couper, M. (1998). Measuring survey quality in a CASIC environment. In *Proceedings of the Survey Research Methods Section, American Statistical Association* (pp. 41–49). Alexandria, VA: American Statistical Association.

Curtin, R., Presser, S., & Singer, E. (2005). Changes in telephone survey nonresponse over the past quarter century. *Public Opinion Quarterly*, 69, 87–98.

Deming, W. E. (1982). *Out of the crisis*. Cambridge, MA: MIT Press.

Groves, R. (2006). Nonresponse rates and nonresponse bias in household surveys. *Public Opinion Quarterly, 70,* 646–675.

Holbrook, A., Krosnick, J., & Pfent, A. (in press). Response rates in surveys by the news media and government contractor survey research firms. In J. Lepkowski, B. Harris-Kojetin, P. Lavrakas, C. Tucker, E. de Leeuw, M. Link, M. Brick, L. Japec, & R. Sangster (Eds.), *Advances in telephone survey methodology*. New York: Wiley.

Juran, J. M. (1992). *Juran on quality by design: The new steps for planning quality into goods and services*. New York: The Free Press.

Keeter, S., Kennedy, C., Dimock, M., Best, J., & Craighill, P. (2006). Gauging the impact of growing nonresponse on estimates from a national RDD telephone survey. *Public Opinion Quarterly, 70,* 759–779.

Link, M., & Mokdad, A. (2004). Are Web and mail modes feasible options for the Behavioral Risk Factor Surveillance System? In S. B. Cohen & J. M. Lepkowski (Eds.), *Eighth Conference on Health Survey Research Methods* (pp. 149–154). Hyattsville, MD: National Center for Health Statistics.

O'Muircheartaigh, C. (1997). Measurement error in surveys: A historical perspective. In L. Lyberg, P. Biemer, M. Collins, E. de Leeuw, C. Dippo, N. Schwarz, & D. Trewin (Eds.), *Survey measurement and process quality* (pp. 1–25). New York: Wiley.

Scheuren, F. (2001). *Macro and micro paradata for survey assessment.* Paper presented at the UN Work Session on Statistical Metadata, Washington, DC.

Trei, L. (2006, September 26). Social science researcher to overhaul survey methodology with $2 million grant. *Stanford Report*. Retrieved July 18, 2007, from http://news-service.stanford.edu/news/2006/september27/krosnick-092706.html

SESSION 5 SUMMARY

Brad Edwards, *Westat*
Martin Barron, *National Opinion Research Center*
Anne B. Ciemnecki, *Mathematica Policy Research, Inc.*

INTRODUCTION

The five presentations in this session emphasized the importance of fully understanding the choices we make as we design health surveys. Researchers have a growing set of options to choose from as they seek to balance the accuracy, timeliness, relevance, accessibility, and comparability of survey data against survey design and data collection costs. The focus of this session was to review information about the relationship between survey design and survey costs and to explore ways to make evidence-based design choices.

MAJOR THEMES

Building a Framework to Evaluate Options

If government agencies are to continue to conduct health surveys, those surveys must offer the highest quality data at affordable costs. To select cost-effective methods, the health survey research community must build an infrastructure that helps funders assess the competing demands of accuracy, timeliness, relevance, accessibility of findings, and comparability of data. Data users must recognize that there is no single optimal design that achieves the gold standard along all of these dimensions. Rather, the best design is the one that best fits the user's data needs and resources. Choices of mode, sample frame, and technology are dynamic, so the infrastructure must provide a framework for assessing the options. It is critical to have as much information as possible to assess the impact of choices on data quality and, more specifically, on nonresponse error, measurement error, and respondent burden.

Finding a Proxy for Nonresponse Bias

Concerns about nonresponse bias are growing, leading to an increasing focus on estimating nonresponse error. However, unlike measurement error, we have limited means of assessing the impact of nonresponse error. Response rates, once regarded as proxies for nonresponse bias, are not only declining but may never have been useful proxies for nonresponse bias. The challenge is that a universally accepted proxy measure of nonresponse bias has not emerged. Investigators are grappling with ways to estimate nonresponse bias, though a true measure of nonresponse bias may be impossible to achieve. Part of the problem is that nonresponse occurs at the unit level, whereas nonresponse bias, when it has been identified, occurs at the item (i.e., variable) level. Despite the continuing decline in response rates, Groves et al. show only weak relationships between response rates and nonresponse bias. OMB has mandated a nonresponse bias analysis for every federally funded contract with a survey response of less than 80%. Most surveys fall below this standard, indicating an urgent need to learn more about nonresponse bias.

Learning More about Mixed-Mode Effects

The choice of survey modes is growing and dynamic. In addition to the traditional mail/phone/in-person options, there are now technologically enhanced self-administered modes, such as Web surveys, IVR, and CASI, all of which are particularly well suited for sensitive items. In addition to improving response rates, alternate and mixed modes are being used to improve efficiency and better match specific data items to quality, reduce respondent burden, and broaden the range of questions that can be asked for a given cost. While these additional options present opportunities, they also increase design complexity and may backfire if few respondents elect a mode that requires high costs to develop. Moreover, little is known about mixed-mode effects.

CURRENT STATE OF KNOWLEDGE

Many researchers have documented the decline of response rates in the United States. The decline has been most prevalent in telephone surveys, but similar, less pronounced, declines have been observed in face-to-face surveys. Since probability samples became dominant in survey research more than 50 years ago, response rates have been considered a proxy for nonresponse bias. Responses rates provide a rough measure of quality, despite growing evidence that they are inadequate for fully capturing all dimensions of quality. Alternatives to response rates as a measure of survey quality have yet to be developed. Research has shown a tenuous connection between response rates and quality, but there is a general sense of declining survey quality and, therefore, a need for a better proxy.

The rapidly changing nature of the survey research field and a decline in the public's willingness to participate in data collection make it increasingly difficult to make informed choices regarding survey design. Methods that worked several years ago no longer work. Over the past decade, cost, timeliness, and response rates have changed at different rates. This upsets the traditional relationships among these dimensions and affects the process of choosing appropriate survey methodology. It also reveals a gap in our knowledge about the trade-offs in survey design today.

The computerization of survey research has created vast quantities of paradata for virtually every survey. All surveys use this data to monitor survey progress, but few use responsive design techniques. Groves has begun to develop a framework for using paradata to inform certain decisions in the survey process. However, a generalized framework for using paradata to improve survey operations and results has yet to be developed.

Despite the growing costs of surveys, response rates have generally declined. Perhaps the best research on the link between the persistent increase in survey cost and decline in survey quality has been made by Curtin, Presser, and Singer (2005). This decoupling of cost and quality leads to difficulties in gauging the relative merits of competing designs. As Brick and Kalton pointed out in this session, not only do aggregate costs vary, but so do cost components. For example, in face-to-face surveys, there are both high fixed costs and high variable costs. In contrast, Web designs have high fixed costs but almost no variable costs. When modes are mixed, the cost calculus becomes even more complex. This phenomenon necessitates a typology of cost across modes if funders are to make informed decisions.

CROSSCUTTING ISSUES

The discussion in this session raised a number of crosscutting themes that may be fertile ground for exploration. These include

- Constraints on the current survey environment (such as IRBs, OMB, and reduced budgets—especially for methods research).
- Increasing interest in mixed-mode designs but very little understanding of mode effects and an increased need to focus on measurement error.
- Increasing interest in maximizing value by adding other data sources to survey self-reports (such as biomarkers, administrative data, and observational data).
- Identifying the users of survey data: trade-offs differ depending on whether one wants to optimize value for the funder, the respondent, or the data collector.

FUTURE RESEARCH

Enhancing our understanding of nonresponse, nonresponse bias, and nonresponders is crucial for the future of survey research. New methods need to be developed. One approach worth exploring is to investigate nonresponse bias in surveys that use sample frames with rich auxiliary data. Another promising approach involves seeding a questionnaire with several items for which answers have a known distribution and then comparing the distribution of responses to the two groups of questions. Our understanding of nonresponse also may be improved with research on inveterate nonresponders. Identifying the characteristics and motivations of nonresponders helps determine whether the nonresponse bias is study specific or generalizable. In addition, research is needed to establish industry standards for the appropriate level of nonresponse analysis required for different surveys (based on response rate, availability of benchmark data, etc.).

More research also is needed on the primary focus of this session: trade-offs in health survey design. One useful starting point for this research would be the creation of a simple trade-off table of cost, quality, and timeliness across survey modes. It would be particularly helpful if those relationships could be quantified, to the extent possible, with input from survey organizations. Such a table would help clients make informed decisions about which mode is most appropriate for them. Further research on the use of paradata also has great potential for improving study design and performance and would allow researchers to make timely and informed decisions while surveys are underway.

PARTICIPANT LIST

Lu Ann Aday
The University of Texas School of Public Health
1200 Herman Pressler St., Rm. E-321
Houston TX 77030
(713) 500-9177
Lu.A.Aday@uth.tmc.edu

Alisha D. Baines
Center for Chronic Disease Outcomes Research
One Veteran's Dr. 152/2E
Minneapolis MN 55417
(612) 467-1424
alisha.baines@med.va.gov

Reg Baker
Market Strategies
20255 Victor Pkwy., Ste. 400
Livonia MI 48152
(734) 542-7640
reg_baker@marketstrategies.com

Kirsten Barrett
Mathematica Policy Research, Inc.
600 Maryland Ave. SW, Ste. 550
Washington DC 20024
(202) 554-7564
kbarrett@mathematica-mpr.com

Martin Barron
National Opinion Research Center
55 E. Monroe, Ste. 1840
Chicago IL 60603
(312) 759-4247
barron_martin@norc.org

Michael P. Battaglia
Abt Associates, Inc.
55 Wheeler St.
Cambridge MA 02138
(617) 349-2425
mike_battaglia@abtassoc.com

Timothy Beebe
Mayo Clinic College of Medicine
200 First St. SW
Rochester MN 55905
(507) 538-4606

beebe.timothy@mayo.edu

Paul Biemer
RTI International and UNC–Chapel Hill
1917 Eagle Creek Ct.
Raleigh NC 27606
(919) 541-6056
ppb@rti.org

Stephen Blumberg
National Center for Health Statistics
3311 Toledo Rd., Rm. 2112
Hyattsville MD 20782
(301) 458-4107
sblumberg@cdc.gov

John Boyle
Schulman, Ronca & Bucuvalas, Inc.
8403 Colesville Rd., Ste. 820
Silver Spring MD 20910
(301) 608-3883
j.boyle@srbi.com

Nancy Breen
National Cancer Institute
6130 Executive Blvd. MSC 7344
Bethesda MD 20892
(301) 496-4675
breenn@mail.nih.gov

J. Michael Brick
Westat and The Joint Program in Survey Methodology
Westat RE 468
1650 Research Blvd.
Rockville MD 20850
(301) 294-2004
mikebrick@westat.com

Julie Brown
RAND Corporation
1776 Main St.
P.O. Box 2138
Santa Monica CA 90407
(310) 393-0144, ext. 6212
Julie_Brown@rand.org

Catherine Burt
National Center for Health Statistics
3311 Toledo Rd.
Hyattsville MD 20782

(301) 458-4126
cwb2@cdc.gov

Vicki Burt
National Center for Health Statistics
3311 Toledo Rd., Rm. 4211
Hyattsville MD 20782
(301) 458-4127
vburt@cdc.gov

Barbara Carlson
Mathematica Policy Research, Inc.
P.O. Box 2393
Princeton NJ 08543
(609) 275-2374
bcarlson@mathematica-mpr.com

Anne Ciemnecki
Mathematica Policy Research, Inc.
600 Alexander Park
Princeton NJ 08540
(609) 275-2323
aciemnecki@mathematica-mpr.com

Llewellyn Cornelius
University of Maryland School of Social Work
525 W. Redwood St.
Baltimore MD 21201
lcornelius@ssw.umaryland.edu

Mick Couper
University of Michigan
Survey Research Center
P.O. Box 1248
Ann Arbor MI 48109
(734) 647-3577
mcouper@umich.edu

Darryl Creel
RTI International
6110 Executive Blvd., Ste. 902
Rockville MD 20852
(301) 770-8229
dcreel@rti.org

Lester Curtin
Centers for Disease Control and Prevention
3311 Toledo Rd.
Hyattsville MD 20782
(301) 458-4172

lrc2@cdc.gov

Marcie Cynamon
National Center for Health Statistics
3311 Toledo Rd., Rm. 2113
Hyattsville MD 20782
(301) 458-4174
mlc6@cdc.gov

Koustuv Dalal
Karolinska Institutet
Norrbacka, 2nd Fl.
Stockholm SE 171 76 Sweden
46-0-8-737-3883
koustuv.dalal@ki.se

Robin D'Aurizio
RTI International
151 Sunset Terrace
Orchard Park NY 14127
(800) 610-2752
robinwrite@aol.com

Michael Davern
University of Minnesota
State Health Access Data Assistance Center
2221 University Ave. SE, Ste. 345
Minneapolis MN 55414
(612) 625-4835
daver004@umn.edu

William Davis
National Cancer Institute
6116 Executive Blvd., Ste. 504
Bethesda MD 20892
(301) 594-3582
davisbi@mail.nih.gov

Don Dillman
Washington State University
Social and Economic Sciences Research Center
P.O. Box 644014
Pullman WA 99164
(509) 335-4150
dillman@wsu.edu

Brad Edwards
Westat
1650 Research Blvd.
Rockville MD 20850

(301) 294-2021
bradedwards@westat.com

Sherm Edwards
Westat
1650 Research Blvd.
Rockville MD 20850
(301) 294-3993
shermedwards@westat.com

Trena Ezzati-Rice
Agency for Healthcare Research and Quality
540 Gaither Rd., Rm. 5038
Rockville MD 20850
(301) 427-1478
trena.ezzati-rice@ahrq.hhs.gov

John Fleishman
Agency for Healthcare Research and Quality
540 Gaither Rd.
Rockville MD 20850
(301) 427-1674
jfleishm@ahrq.gov

Jack Fowler
University of Massachusetts Boston
Center for Survey Research
100 Morrissey Blvd.
Boston MA 02125
(617) 287-7200
floyd.fowler@umb.edu

Martin Frankel
Baruch College, CUNY
17 Lexington Ave.
New York NY 10010
(646) 312-3378
martin_frankel@baruch.cuny.edu

Patricia Gallagher
University of Massachusetts Boston
Center for Survey Research
100 Morrissey Blvd.
Boston MA 02125
(617) 287-7200
patricia.gallagher@umb.edu

Joe Gfroerer
Substance Abuse and Mental Health Services Administration
1 Choke Cherry Rd., Rm. 7-1015

Rockville MD 20857
(240) 276-1262
joe.gfroerer@samhsa.hhs.gov

David Grant
UCLA Center for Health Policy Research
10960 Wilshire Blvd., Ste. 1550
Los Angeles CA 90024
(310) 794-0916
dgrant@ucla.edu

Robert Groves
University of Michigan
Institute for Social Research
426 Thompson St.
Ann Arbor MI 48106
(734) 764-8365
bgroves@isr.umich.edu

Janet Harkness
University of Nebraska-Lincoln
200 N. 11th St.
Lincoln NE 68588-0241
(402) 458-2035
jharkness2@unl.edu

Art Hughes
Substance Abuse and Mental Health Services Administration
1 Choke Cherry Rd., Rm. 7-1017
Rockville MD 20857
(240) 276-1261
art.hughes@samhsa.hhs.gov

Clifford Johnson
National Center for Health Statistics
3311 Toledo Rd., Rm. 4205
Hyattsville MD 20782
(301) 458-4292
clj1@cdc.gov

Timothy P. Johnson
University of Illinois at Chicago
Survey Research Laboratory
412 S. Peoria, 6th Fl.
Chicago IL 60607
(312) 996-5310
timj@srl.uic.edu

Graham Kalton
Westat

1650 Research Blvd.
Rockville MD 20850
(301) 251-8253
grahamkalton@westat.com

Judith Kasper
Johns Hopkins University
Bloomberg School of Public Health
641 N. Broadway
Baltimore MD 21205
(410) 614-4016
jkasper@jhsph.edu

Joel Kennet
Substance Abuse and Mental Health Services Administration
1 Choke Cherry Rd., Rm. 7-1009
Rockville MD 20857
(240) 276-1265
joel.kennet@samhsa.hhs.gov

Ronald Kessler
Harvard Medical School
180 Longwood Ave., 2nd Fl.
Boston MA 02115
(617) 432-3587
kessler@hcp.med.harvard.edu

Barbara Koenig
Mayo College of Medicine
200 First St. SW
Rochester MN 55905
(507) 538-1168
koenig.barbara@mayo.edu

Susan Krebs-Smith
National Cancer Institute
6130 Executive Blvd. MSC 7344
Bethesda MD 20892
(301) 496-4766
sk52r@nih.gov

Alice Kroliczak
Health Resources and Services Administration
5600 Fishers Ln.
Rockville MD 20857
(301) 443-3592
akroliczak@hrsa.gov

Dick Kulka
Abt Associates, Inc.

4620 Creekstone Dr., Ste. 190
Durham NC 27703
(919) 294-7710
richard_kulka@abtassoc.com

Amy Ladner
RTI International
701 13th St., NW, Ste. 750
Washington DC 20005-3967
(202) 728-1947
ladner@rti.org

Robert Lee
University of California–Berkeley
Survey Research Center
2538 Channing Way, #5100
Berkeley CA 94720
(510) 642-0871
boblee48@berkeley.edu

Michael Link
Centers for Disease Control and Prevention
4770 Buford Highway NE, MS K66
Atlanta GA 30341
(770) 488-5444
awi5@cdc.gov

John Loft
RTI International
230 W. Monroe St.
Chicago IL 60606
(312) 456-5241
jloft@rti.org

Robert Mills
Health Resources and Services Administration
5600 Fishers Ln.
Rockville MD 20857
(301) 443-3899
mills@hrsa.gov

Judith Mopsik
Abt Associates, Inc.
6415 79th St.
Cabin John MD 20818
(301) 634-1831
judie_mopsik@abtassoc.com

Richard P. Moser
National Cancer Institute

6130 Executive Blvd., Rm. 4052
Bethesda MD 20892
(301) 496-0273
moserr@mail.nih.gov

Kathleen O'Connor
National Center for Health Statistics
3311 Toledo Rd., Rm. 2114
Hyattsville MD 20782
(301) 458-4181
koconnor1@cdc.gov

Diane O'Rourke
University of Illinois at Chicago
Survey Research Laboratory
505 E. Green St., Ste. 3
Champaign IL 61820
(217) 333-7170
dianeo@srl.uic.edu

Larry Osborn
Abt Associates, Inc.
640 N. LaSalle St., Ste. 640
Chicago IL 60610
(312) 867-4071
larry_osborn@abtassoc.com

Jennifer Parsons
University of Illinois at Chicago
Survey Research Laboratory
412 S. Peoria, 6th Fl.
Chicago IL 60607
(312) 996-5300<
jparsons@srl.uic.edu

Joanne Pascale
U.S. Census Bureau
Statistical Research Division FOB4-3134
Washington DC 20233
(301) 763-4920
joanne.pascale@census.gov

Allison Plyer
Greater New Orleans Community Data Center
1600 Constance St.
New Orleans LA 70130
(504) 304-8260, ext. 225
allisonp@gnonkw.org

Colleen Porter

University of Florida
Community Dentistry and Behavioral Science
P.O. Box 103628
Gainesville FL 32610
(352) 273-5979
cporter@dental.ufl.edu

Paul Pulliam
RTI International
230 W. Monroe St., Ste. 2100
Chicago IL 60606
(312) 456-5258
pulliam@rti.org

Todd Rockwood
University of Minnesota
Center for Survey Research in Public Health
420 Delaware St. SE
Minneapolis MN 55455
(612) 625-3993
rockw001@umn.edu

Dianne Rucinski
University of Illinois at Chicago
1747 W. Roosevelt
Chicago IL 60608
(312) 355-1769
drucin@uic.edu

Lisa Schwartz
Mathematica Policy Research, Inc.
600 Alexander Park
Princeton NJ 08540
(609) 945-3386
lschwartz@mathematica-mpr.com

Eleanor Singer
University of Michigan
Survey Research Center
P.O. Box 1248
Ann Arbor MI 48106
(734) 647-4599
esinger@isr.umich.edu

James Singleton
Centers for Disease Control and Prevention
1600 Clifton Rd. NE, Mailstop E-62
Atlanta GA 30333
(404) 636-8560
xzs8@cdc.gov

Stephen Smith
National Opinion Research Center
55 E. Monroe
Chicago IL 60603
(312) 759-4023
smith-stephen@norc.org

Edward Spar
Council of Professional Associations on Federal Statistics
2121 Eisenhower Ave., Ste. 200
Alexandria VA 22314
(703) 836-0404
copafs@aol.com

John Thompson
National Opinion Research Center
55 E. Monroe, Ste. 4800
Chicago IL 60603
(312) 759-4211
thompson-john@norc.org

Jasmin Tiro
National Cancer Institute
6130 Executive Blvd., EPN 4130A
Bethesda MD 20892
(301) 451-5040
tiroj@mail.nih.gov

Roger Tourangeau
University of Maryland
Joint Program in Survey Methodology
1218W LeFrak Hall
College Park MD 20742
(301) 314-7984
rtourangeau@survey.umd.edu

Sally Vernon
University of Texas–Houston
School of Public Health
7000 Fannin, Ste. 2560
Houston TX 77030
(713) 500-9760
Sally.W.Vernon@uth.tmc.edu

Kay Wanke
National Institute on Drug Abuse
6001 Executive Blvd., Ste. 5146
Bethesda MD 20892
(301) 451-8663

wankek@nida.nih.gov

Cheryl Wiese
Group Health Center for Health Studies
1730 Minor Ave., Ste. 1600
Seattle WA 98101-1448
(206) 442-4041
wiese.c@ghc.org

Kirk Wolter
National Opinion Research Center
55 E. Monroe St., Ste. 4800
Chicago IL 60603
(847) 759-4206
wolter-kirk@norc.uchicago.edu

Elizabeth Zell
Centers for Disease Control and Prevention
1600 Clifton Rd., MS-C09
Atlanta GA 30333
(404) 639-4710
ezr1@cdc.gov