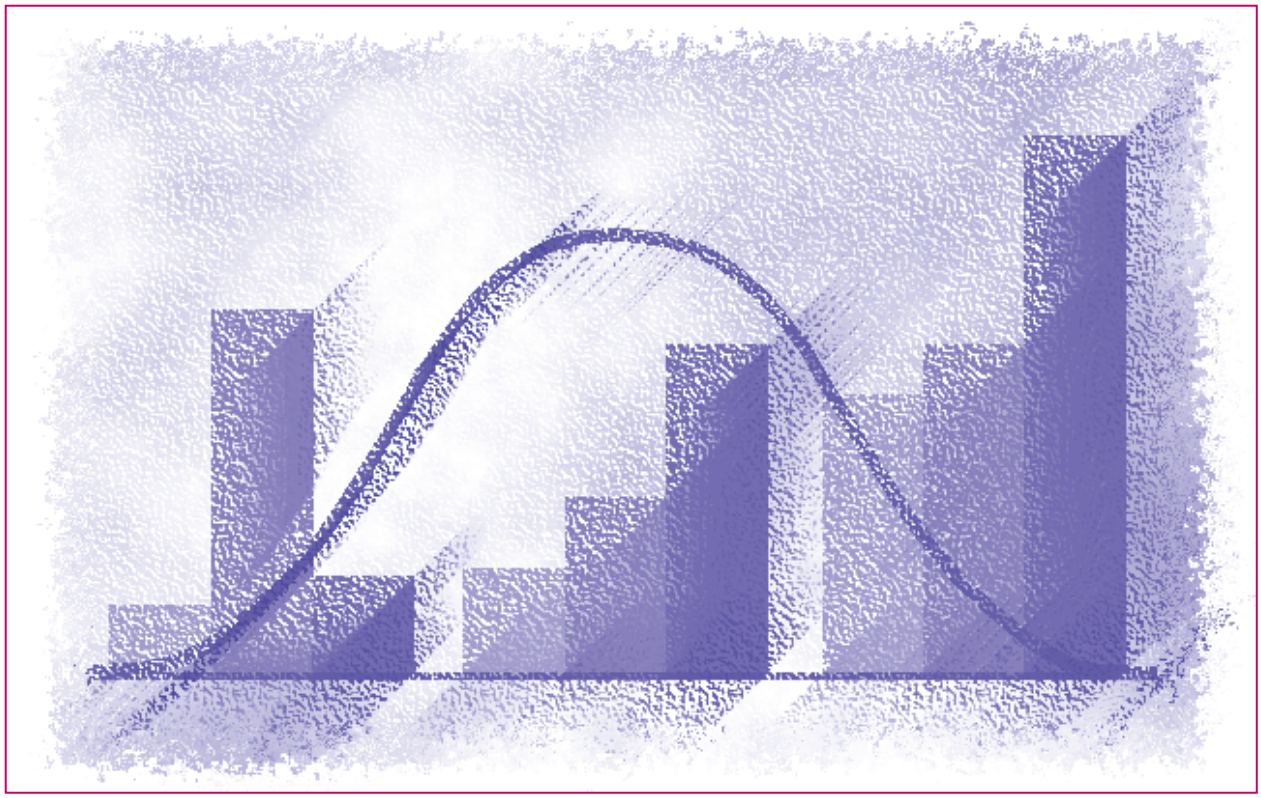

HEALTH SURVEY RESEARCH METHODS

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

Tenth Conference on

HEALTH SURVEY RESEARCH METHODS

Edited by
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DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention
National Center for Health Statistics
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Disclaimer: This report contains the papers and formal and floor discussions presented at the 10th Conference on Health Survey Research Methods. 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. The findings and conclusions in this report are those of the authors and do not necessarily represent the views or opinions of the National Center for Health Statistics (NCHS) or the Centers for Disease Control and Prevention (CDC).

Contents

Introduction

We are pleased to present this volume of papers and discussion from the 10th Conference on Health Survey Research Methods, which was held in Peachtree City, Georgia from April 8-11, 2011. It has now been 36 years since the first such meeting was held in 1975. While the specific methods and research questions have evolved considerably over this period, the importance of these meetings for summarizing current knowledge and identifying future research priorities remains.

This conference almost did not happen. Spending authorization for the federal government was due to expire at midnight on the first evening of conference, and it was unclear that Congressional leaders would approve a new budget. The participation of federal employees, who represented a quarter of those planning to attend the conference and a third of the papers to be presented, was thus placed in jeopardy. Conference organizers reviewed options, including canceling or postponing the conference, in the final days before the meeting was to take place. Acting in an uncertain environment, we elected to proceed with the original conference plan that had been developed by the Steering Committee over the previous two years and hope for the best. As the Conference's opening keynote addresses were given, negotiations continued in Washington. Our only certainty was that one of two things would happen the next morning: either some conference participants who represented federal agencies would be required to leave the conference (due to a shutdown of the federal government), or some, who had delayed their departures due to uncertainty, would arrive. At 12:40 A.M., 40 minutes after the expiration of federal spending authority, Congress agreed to a Continuing Appropriations Act (H.R. 1363), and a shutdown was averted.

The conference proceeded on schedule, with five sessions and 27 formal presentations over the ensuing two-and-a-half days. All papers originally scheduled for delivery at the conference were presented, in some cases by surrogates stepping in for federal employees who were unable to make travel arrangements subsequent to the budget agreement. The sessions on the first full day of the conference focused on specific health survey content domains and measurement issues. The second day targeted specific methods and data sources, including online panels and administrative records. The final session took the conference participants further beyond traditional data collection methods to personal digital assistants, social media, and virtual worlds. "Fitness for purpose" was a recurring theme of this conference, as participants identified the pros and cons of alternatives to conventional methods and sources and types of data. Another recurring theme was the potential for innovative statisticians to find ways to reduce survey error through measurement models, imputation, and weighting, albeit with increased demands on the skills of data analysts.

The conference included three keynote speeches. The opening address by Jack Fowler provided a broad historical overview of this conference series by someone who has attended all but one of them. The next address by Ed Sondik, director of the National Center for Health Statistics, highlighted the ongoing needs for quality health survey data to address public health priorities and inform health reform policy, yet he also emphasized that budget concerns lead to significant uncertainty at federal health agencies (see "shutdown, government") and the need to leverage investments in existing data systems. Norman Bradburn closed the conference with an integrative summary of the topics covered by the various paper presentations, and he used them to help frame a future research agenda. We were grateful and honored that each agreed to speak at this conference.

It is with great pleasure that we acknowledge the generous support of a variety of public and private organizations who contributed financially to this conference. These include Abt Associates, the Agency for

Healthcare Research and Quality (AHRQ), the Battelle Centers for Public Health Research and Evaluation, ICF/Macro International, the Lewin Group, Mathematica Policy Research, Inc., the Mayo Clinic, the National Center for Health Statistics, the National Cancer Institute, NORC at the University of Chicago, the Rand Corporation, RTI International, the Substance Abuse and Mental Health Services Administration, SSRS/Social Sciences Research Solutions, the University of Michigan Institute for Social Research, and Westat. Without their support, the conference would not have happened.

We are also grateful to have had the opportunity to work with an unusually strong and supportive Steering Committee of individuals who insured that the diverse perspectives of federal and non-federal research organizations were represented throughout the planning and organizing process. Their knowledge and counsel proved invaluable and vital to the success of the conference, as did their leadership in organizing the various conference sessions and their collective willingness to step forward to help address the various logistical challenges that the potential government shutdown presented to us immediately before the start of the conference. Members of this committee included Timothy Beebe, Jeanine Christian, Anne Ciemnecki, Michal Davern, David Dutwin, Brad Edwards, Trena Ezzati-Rice, Joe Gfroerer, Richard Kulka, Jim Lepkowski, John Loft, Judie Mopsik, Ed Spar, and Gordon Willis.

A great debt of gratitude is also due to Diane O'Rourke, Conference Organizer for this as well as the previous four conferences in this series. Her professionalism, organizational skills, careful planning, and ability to "herd cats" insured a successful and productive meeting. Thank you, Diane. We are also very appreciative of the excellent support provided by Lisa Kelly-Wilson, who has now assisted Diane in successfully coordinating two Health Survey Research Methods conferences and has taken on responsibility for editing the proceedings of the last three conferences. We also must acknowledge Nancy Lockmiller, who handled all of the details that none of us think about but desperately need to have addressed in a competent manner. A special thanks also to Ed Spar at COPAS, who came to our rescue by providing us with a stable and transparent mechanism for collecting and holding financial contributions to this conference, which came from 15 organizations. As in the past, the federal health agencies (most notably, the Agency for Healthcare Research and Quality, the National Cancer Institute, and the National Center for Health Statistics) were steadfast supporters.

The remainder of this volume chronicles the rich papers and provocative discussions that took place during the course of this meeting. We note that the Introduction to the proceedings from the First Conference on Health Survey Research Methods in 1975 concluded that "this report is tentatively planned as Volume 1 of a series of such conference proceedings on advances in health survey research methods." We respectfully submit Volume 10.

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KEYNOTE: A Brief History of the Nine Conferences on Health Survey Research Methods

Floyd J. Fowler, Jr. (University of Massachusetts-Boston)

Airlie House (now known as the Airlie Center) is located in a rural setting about 50 miles south of Washington, DC. In 2011, it is a state-of-the-art conference center, at least as far as I could tell from its Web site. However, my memory is that the rooms were pretty spartan in 1975: all participants shared a room with two twin beds, and the rooms lacked televisions and telephones so attendees could focus on the subject of their conference.

In early May 1975, the Washington Bullets were in the NBA playoffs. The Bullets ended up losing in the finals to San Francisco, but they were winning at the time of the conference. In the evening hours, following the fortunes of the Bullets on the television in the pub was a distraction for some of those from DC. However, for the most part, the first conference on health survey research methods was a total immersion in methodological issues for the better part of three days.

Then, as now, the two federal agencies most concerned with using surveys to collect health-related data were the National Center for Health Statistics and the National Center for Health Services Research (since transformed into the Agency for Healthcare Research and Quality). The two agencies jointly sponsored and funded the conference.

The central idea of the conference was to bring together a range of people from different disciplines who were active in survey methods research to share ideas about survey methods. Then, as now, research about survey methods was presented at a variety of meetings and published in a wide range of journals. One result of the conference was to create a document that summarized the state of current knowledge and an agenda for needed research about how to collect survey data.

Fifty-five people attended that first conference. The conference consisted of four half-day sessions. There were no formal papers presented. Rather, the session leaders laid out a summary of some of the things that they thought had been established and a set of issues, which became the agenda for a group discussion. At the end of each session, an effort was made to summarize what was known, what questions remained, and what priorities should be for further research.

For each session, there was a rapporteur—a person responsible for recording the elements of the discussion. At the end of the conference, the session chair and rapporteur were responsible for writing up a summary of the session, including the discussion, for inclusion in the conference report before they left the conference.

I believe that Norman Bradburn and I are the only people who attended the Airlie House conference who also are attending the 10th conference in 2011. LuAnn Aday and Don Dillman, who were also at Airlie House, were invited but unable to attend this conference.

The second conference was held in Williamsburg, Virginia, in 1978. It was larger, going up from fewer than 60 to over 80 attendees. Another change for this conference was that each session was introduced by a formal "commissioned" paper summarizing a set of issues to be addressed, and there was a formal discussion paper for each "problem" paper, but the emphasis was still on the floor discussion to generate a summary of the state of knowledge. The idea of having rapporteurs to capture the key elements and conclusions in the proceedings was retained.

The third conference was moved to Reston, Virginia, closer to Washington to save travel money for government attendees. The third conference also further amended the initial structure by having multiple papers presented at each session, along with one or two formal discussion papers per session. One of the most obvious effects of these changes in the program is that the published conference proceedings grew from about 60 pages the first year and 90 pages for the second conference to about 300 pages for the third. The proceedings have not come in at fewer than 200 pages since the second conference. The format change initiated in the third conference of having several formal papers and discussion papers for each session has been maintained ever since.

One other historical item of note: The first three conferences all had the same six nongovernmental members of the planning committee. However, shortly before the third conference, two tragedies occurred when Leo Reeder died in an airplane crash and Elijah White, who had been the NCHS representative on the second and third planning committees, was killed in an auto accident. Thus, after the third conference, the planning committee began to expand and evolve.

The fourth conference, in 1982, near the beginning of the first Reagan administration, was held in a time of fiscal austerity. For the first time, outside help, in the form of a grant from the Milbank Fund, was needed to supplement funds available from NCHS and NCHSR. The location was right outside Washington, DC. Attendees stayed in a 4-H Club Conference Facility. Austerity also was reflected in the fact that those who lived in the DC area were encouraged to eat and sleep at home, rather than stay at the conference facility. Proximity to DC also made it hard for some attendees to stay away from their offices for two and a half days. Altogether, the fourth conference was probably the least conducive to focused attention on methodology.

The longest gap in the series was between conferences four and five. However, the conference was renewed in 1989. This time the conference planners addressed the temptations of those in DC to head off to work in a big way: the conference was held high in the Rocky Mountains, a good long ride from the Denver airport. The format was now set, with most sessions consisting of several research papers and one or two formal discussants but still plenty of emphasis on the floor discussion.

The sixth conference also was held in the Rocky Mountains. The main innovation associated with conference six was that the number of federal sponsors began to grow. While NCHS and, by then, AHCPR, were still core sponsors, for the first time they were joined by several other federal agencies. A trend since the sixth conference has been a growing list of federal agencies that have participated in supporting the conference and that participate in planning the conference themes.

Conference six was also notable as the kickoff of the Diane O'Rourke era. Every conference has had a conference chair, and for the first six conferences, the chair's institution received the grants that funded the conference and administered the expenses connected with the conference. Typically, someone who worked with the chair was responsible for managing the conference logistics: everything from coordinating communication with the participants to making arrangements for hotels, for travel, and for managing the conference funds. Diane played that role in 1993, when the University of Illinois was the "host" organization. However, Diane had such an aptitude for, and interest in, managing the conference details that she was retained in the role of conference coordinator for the seventh conference, the eighth, the ninth, and now the tenth. Her place in the history of these conferences is now firmly established.

I'd like to return to the visionaries who started this conference some 36 years ago:

- The Center Directors: Dorothy Rice of NCHS and Gerald Rosenthal of NCHSR.
- The NCHS staff members who were on the original planning committees: Robert Fuchsberg and Elijah White from NCHS; and Sherman Williams, Bill Kitching, Bill Lohr, and Joseph de la Puenta from NCHSR.
- The original rapporteurs, who inspired all the rapporteurs who followed in their footsteps: Ron Anderson, Jack Fowler, Monroe Sirken, and Kirk Wolter.
- And the original nongovernmental members of the first three conference planning committees: Leo Reeder, Charles Cannell, Bernard Greenberg, Dan Horvitz, and Seymour Sudman.

These people created a conference that is different from all others. A few things have changed:

1. There are now formal papers rather than just a discussion leader with an outline of issues.
2. The founders envisioned a biennial conference, but the average has been about every 3.5 years.
3. There are more sponsors.
4. The conference is bigger, largely reflecting representation from a larger group of sponsors.

But look at all the features that have endured:

1. The conference is by invitation only.
2. All invitees have their expenses covered.
3. The conference is entirely in plenary session.
4. All attendees are expected to stay for the entire conference because they are attending not just to listen but to contribute to the discussions.
5. Each session has a focus; the topics are integrated, not just a set of papers.
6. There are invited discussants for each session to help highlight the key theme and issues.
7. Floor discussion is an important part of the conference, and there are invited rapporteurs whose job it is specifically to capture the discussion.
8. Chairs and rapporteurs have to stay after the conference to complete a draft of their summary of the discussion and the key takeaway points from each session.
9. The proceedings are published, and they include the chair's summary of the key methodological conclusions and needs for research that emerged from the conference.
10. While a number of federal agencies contribute to the sponsorship of the conference, and their support is critical, the National Center for Health Statistics and the Agency for Health Research and Quality, the grandchild of the National Center for Health Services Research, are still core sponsors.

The fact that the key features of a conference that the founders envisioned 36 years ago are still largely intact is a great tribute to their vision. But we should not focus solely on the structural features of the conference.

The most important function of this conference is to remind those who collect and disseminate health data that methods matter. In all times and places, there will be new challenges to old methods of doing surveys. There will be pressures to collect more data with less money, sometimes in ways likely to compromise the quality of those data. The federal government, directly and through grants and contracts to others, collects a tremendous amount of survey data, seemingly more each year. This conference brings together those who think the most about survey error and provides an environment in which they can talk together for almost three days about what they know and how methodology affects the confidence we can have in our data. This conference provides a periodic reminder to those who collect and use survey data that we must continuously take stock and review our methods to make sure they are as good as they can be. This conference provides a research agenda to encourage investing some of the money devoted to collecting new data in studies of our methods. This conference is a time to remember that collecting a lot of data is not the point; the point is to collect good quality data that accurately informs us about issues that matter. And that is what these Heath Survey Research Methods Conferences are all about.

SUMMARY OF WELCOME AND KEYNOTE SESSION

Gordon Willis (National Cancer Institute) and **Brad Edwards** (Westat)

Jack Fowler provided a recap of the nine previous Health Survey Research Methods (HSRM) conferences stretching back to 1975, and Edward J. Sondik spoke of anticipated future data needs. Chair Stephen Blumberg opened the floor for discussion. The discussion focused on one major theme: the importance of social network data.

What can we as researchers do to make data collection on social networks more productive for policymakers? The federal government has not made a commitment to using social network data despite its potential. Two related examples are wellness and obesity prevention. We can easily collect data on what an individual physician does to counsel patients on wellness behaviors, but we rarely know what influences that physician. What meeting is he or she attending? To what other practitioners is he or she talking? What are other physicians in his or her practice doing about wellness?

While we all agreed that we are influenced by our social inputs, we also admitted a lack of knowledge about the social influences we should study. Ed Sondik mentioned that there are papers from the Framingham studies but not much beyond that. The National Institute on Aging's longitudinal National Social Life, Health, and Aging Project and the National Health and Aging Trends Study are addressing social networks, but there is little or no focus on social network research across the federal statistical agencies.

The behavioral data we could collect are not complex. While we do know it would cost more money (as any additional data collection would), we do not know precisely what is influential and how we would use the data. We need to learn more about the value of social networks and associated data for decision making.

Jack Fowler challenged the group to talk to respondents and proxies about what influences their lives. Ed Sondik agreed, using the county he lives in as an example, and avowed that having these data would lead to better decision making at the state and county levels. Such data collection requires partnering with respondents and data users in communities.

The private sector already is mining massive private databases to study social networks. A famous example is telephone record detail files. By examining who is calling whom, one can see what influential nodes exist in a city. Then, the approach is to influence the influencers. It is a way to leverage information dissemination. This is not part of the standard survey model and carries large privacy issues. But the data are there and are already being used by the private sector.

Most of these data are collected passively. Most of the time, we (as respondents) are unaware that any data are being collected about our behaviors. Consent to this data collection is not well informed, and often the data are shared with others without our consent. While these data are prolific, the quality metrics are different from those typically used in health survey research methods, and health survey researchers are uninformed about them.

Ed Sondik and others noted that other data already exist that could also inform social network studies, but these data are largely untapped for this purpose. Numerous NCHS longitudinal studies collect household rosters. These data on population dynamics are quite valuable and worth pursuing, but there are barriers to use. Because of the large amount of resources needed for data collection, resources for analysis of the data are limited. Second, much of this information is not accessible to those outside the agency. Dr. Sondik emphasized the need for intramural budget allocations across the federal statistical agencies to work

with social network data. He hopes this idea will move forward with support from Bob Groves at the Bureau of the Census. Perhaps it could begin with National Institutes of Health staff.

This dynamic discussion addressed a unique need for future data exploration and set the stage for the five sessions that followed.

A research agenda on social networks and networking and their potential role in survey research could be drafted from this discussion, to be refined and explored before the 11th HSRM conference three or four years from now. Here are some questions to begin the work:

1. How can data collection on social networks be made more productive for HSRM and policymakers?
2. What mechanisms and approaches in the public sector might accelerate health survey researchers' use of social network data?
3. How do social networks work today?
4. What patterns of communication nodes and information exchange occur among network members across various health-research topics (for example, health care use, prevention, specific diseases)?
5. What can we learn quickly from the private sector about social networks?
6. How have individuals' lives changed as a result of participation in today's communication networks?
7. What can be said about trends in social networks that might be helpful in positioning health survey research methods in the next decade?
8. How can data currently housed in the federal agencies be mined to advance health survey research knowledge? What approaches might leverage and accelerate this mining across agencies?
9. How can we engage respondents and communities in research on social networks?

SESSION 1: Advances in Measuring Health Status and Health Behaviors

ORGANIZERS: Jeanine Christian (Battelle), **Anne Ciemnecki** (Mathematica), and **Joe Gfroerer** (SAMSHA)
CHAIR: Anne Ciemnecki

Advances in Survey Assessment of Disability in Older Adults: Measuring Physical and Cognitive Capacity in the National Health and Aging Trends Study

Judith D. Kasper (Johns Hopkins University), **Brad Edwards** (Westat), **Vicki A. Freedman** (University of Michigan), **Christopher L. Seplaki** (University of Rochester), **Carlos Weiss** (Michigan State University), **Michelle Carlson** (Johns Hopkins University), **Tamara Bruce** (Westat), **Jack M. Guralnik** (Consultant), **Brenda L. Plassman** (Duke University), **Robert Wallace** (University of Iowa), **Marlene Niefeld** (Johns Hopkins University), and **Vijay Varma** (Johns Hopkins University)

The implications of disability trends for older adults grow in significance as the population ages (IOM, 2007). In studying late-life disability, a key resource has been the National Long-Term Care Survey (NLTCS). Studies based on the NLTCS represent milestones in identifying late-life disability trends (Manton, Corder, & Stallard, 1993, 1997; Manton, Gu, & Lamb, 2006). The National Health and Aging Trends Study (NHATS) is a new longitudinal national survey of persons 65 and older that is a successor to the NLTCS. Focused on functional changes in daily life, NHATS draws on recent comprehensive frameworks for conceptualizing disability (Freedman, 2009; Jette, 2009) and is designed to support research on disability pathways at the individual level (Fried, Bandeen-Roche, Chaves, & Johnson, 2000; Gill, Gahbauer, Allore, & Han, 2006), as well as investigation of the factors that are driving disability trends.

The NHATS framework treats disability as encompassing several domains—capacity to do activities, whether and how activities are done, and accommodations made to bridge gaps between capacity and the demands of activities. This paper will focus on one key component of the NHATS framework—measures of capacity—and, in particular, the use of performance-based capacity assessments that are newer to national surveys and complex to administer. Although not the first national survey to administer such tests, NHATS includes a broad array of both physical and cognitive capacity measures and is unique in planning to conduct these assessments annually. We present in this paper an overview of NHATS capacity measures, administration protocols, and results regarding administration using data from two pilot studies conducted in spring 2010 (n = 326) and winter 2011 (n = 120).

CAPACITY MEASURES IN NHATS

Conceptual Importance of Measuring Capacity

The NHATS disability framework (Freedman, 2009) is a blend of Nagi's widely used model (1965) and the more recent language and perspective of the World Health Organization's International Classification of Functioning, Health, and Disability. We explicitly distinguish between measures of capacity—the building blocks for activities—and what is actually done within an individual's environment (activities). Measures of capacity over time are key elements in understanding individual patterns of progression to activity limitations. Accommodations of various types—devices including technology, environmental modifications, and personal help—also may be adopted to fill the gap between capacity and doing activities that are necessary or valued. Capacity measures are important, then, for tracking trends in function that are independent of environmental changes or accommodations, for understanding the disablement process, and as targets for interventions to prevent or slow disability (LIFE Study Investigators, et al., 2006).

Table 1. NHATS Sensory, Physical, & Cognitive Capacity Measures, by Type of Administration

	Self-Report	Performance-Based
Sensory Capacity	Hearing Vision	
Physical Capacity		
Upper Extremity	Able to: • put book on shelf/reach overhead? • open jar[1]/grasp small object?	Grip strength
Lower Extremity	Able to: • walk 6/3 blocks? • kneel/bend over? • lift & carry 20/10 lbs.? • walk up 20/10 stairs?	Walking speed Balance stands • side by side • semi-tandem • full tandem • one leg, eyes open • one leg, eyes closed
Other		Chair stands Peak air flow
Cognitive Capacity		
Memory	At present time? Memory problems interfere with activities? Memory compared to 1 year ago?	Ten-word recall • immediate • delayed
Orientation		Day of week Date (month, day, year) Naming president Naming vice president
Overall Cognitive Screening/Executive function		Clock-drawing test
Attention & Interference/Executive function		Stroop test (computerized)

[1] Revised to read "open a jar using just your hands" following the Validation Study.

Self-Report & Performance-Based Approaches to Assessment

Self-report measures of physical capacity—for example, questions about reaching overhead or lifting a ten-pound weight (e.g., grocery bag)—often are included in population-based surveys. In recent years, performance-based measures of physical capacity, including tests of balance or strength, have become more common in study protocols for older people. Research by Guralnik and colleagues (1996) has shown these types of physical capacity measures to be strong predictors of subsequent disability and mortality. Self-report measures of cognitive capacity are less common in surveys, with the exception of questions about memory (e.g., How would you rate your memory?). Performance-based measures of cognitive capacity (for example, tests of working memory), drawn primarily from neuropsychology, have been adapted for computer-assisted personal interviewing (CAPI) administration in surveys (e.g., Health and Retirement Survey [www.hrsonline.isr.umich.edu], Survey of Health and Ageing in Europe [www.share-project.org]).

One appeal of performance-based measures of capacity is that they provide a direct assessment of function rather than one filtered through a subject or proxy's perspective. Self-report of physical function in particular can require speculation—for example, someone who doesn't carry the groceries herself is asked to indicate how difficult it would be to lift and carry a ten-pound grocery bag. However, administration of performance-based assessments is substantially more complex than self-report, especially in the context of home-based data collection.

NHATS Assessments

NHATS uses a mix of self-report and performance-based capacity measures as shown in Table 1 on the preceding page. The selection of self-report and performance measures of capacity for NHATS were informed by prior studies including the Women's Health and Aging Study (WHAS) (Guralnik, Fried, Simonsick, Kasper, & Lafferty, 1995; Simonsick et al., 1997) and the Health and Retirement Survey, among others. Many of the measures being used in NHATS reflect important modifications, however, while others are new. Where possible, measures were selected to capture a broad spectrum of capacity, both high and low functioning (Freedman et al., 2011). In selecting performance-based measures, consideration was given to achieving a representation of all major physiologic systems, learning from past attempts to gather and analyze such data through review of published reports and directly contacting investigators, and the need to consider tradeoffs between gathering more in-depth information regarding performance on the one hand and participant burden and feasibility in a home setting on the other.

Table 1 shows the full array of capacity measures being administered in NHATS. As shown, sensory capacity is assessed only through self-report. Administration of performance-based testing of vision or hearing still requires equipment and training that is beyond the reach of in-home surveys conducted by lay interviewers. Physical capacity is assessed for lower and upper extremities through self-report (Freedman et al., in press) and through performance-based tests that are predictive of disability and are components of the Short Physical Performance Battery (Guralnik et al., 1994) and of a widely used frailty construct (Bandeen-Roche et al., 2006; Fried et al., 2001). Peak air flow, predictive of mortality (Melzer, Lan, & Guralnik, 2003), is included as well. Results of the physical performance assessments (completed or attempted but not completed) and reasons assessments were not done are recorded by interviewers in the NHATS Activities Booklet (available at NHATS Activities Booklet (available at www.nhats.org).

Innovations in measuring cognitive capacity in the NHATS include a clock-drawing test and a computerized version of the Stroop test. Other cognitive assessments included are measures of orientation (date/day of the week; naming the president and vice president) and the immediate and delayed ten-word recall (memory) that are more standard in surveys.

The clock-drawing test has been widely used in both clinical and research settings as a part of overall cognitive screening (Shulman, 2000), but it has not been used in a national survey to date. It is a complex nonverbal task involving planning and a range of other cognitive skills that are elements of executive function; an added benefit is that it is less influenced by education than some other screening instruments. The Stroop test, which was developed in the 1930s, measures inhibition, which is a component of executive function. It traditionally is administered with letters and words printed in color on paper. When given in this fashion, the test can be frustrating; subjects often lose their place on the page and have a sense of failure upon finishing. NHATS employs a computerized version of the Stroop test developed by Carlson (Stroop Cognitive Frailty Instrument, CFI) and used in two prior intervention trials (Carlson et al., n.d.). The application mimics a game and takes a maximum of six minutes. The respondent holds a color-coded key pad that is wirelessly connected to the interviewer's laptop computer to press one of three colors that corresponds to the color of letters or words shown on the computer screen. The Stroop CFI offers a number of practical and methodological advantages in that it provides standardized administration, automated data storage, and greater precision in measurement of participant response (to milliseconds), thus reducing the number of trials needed to assess cognitive ability. For NHATS, we measure the participant's ability to maintain a high level of performance on attention under two conditions—nondemanding or "easy" (e.g., naming the color of strings of Xs) vs. demanding or "difficult" (e.g., color words shown in a conflicting color—"red" shown in the color blue).

NHATS APPROACH TO ADMINISTERING PERFORMANCE-BASED CAPACITY ASSESSMENTS

Implementation of performance measures of capacity, both physical and cognitive, in a large national survey of several thousand people is challenging on several fronts. These assessments were developed in clinical or laboratory settings for the most part. Adaptation for in-home data collection as part of a national survey conducted by lay interviewers requires attention to several issues: interviewer training, standardizing administration, safety of respondents, and respondent reactions.

Interviewer Training

Conducting physical performance tests requires interviewers to use a variety of equipment including stopwatches, hand dynamometers, and peak air flow meters. In addition, for activities like chair stands and walking speed, interviewers need to navigate unfamiliar environments to identify an appropriate chair and space for the activities, as well as kneel on the floor to set up the walking course. These activities represent departures from the usual question-and-answer interviewing task and result in a broader and more complex scope of demands on NHATS interviewers. Although several of the cognitive assessments are CAPI-based questions, the clock-drawing test involves a special form and erasable pen; for some assessments, the laptop screen needs to be hidden from the respondent, but for the Stroop test, the respondent has to watch the screen. Instructions to respondents for some of these tests can be uncomfortable for interviewers—for example, telling respondents not to look at a calendar or watch when answering "What is today's date?" or that words cannot be written down as aids during the memory assessment.

NHATS uses a video showing administration of the physical performance assessments in the interviewer recruitment process so candidate interviewers understand the range of tasks. Interviewer training for the physical performance tests makes use of practice but also includes a formal certification process to insure that all components of the protocol, including maintaining safety and following test administration standards, are followed.

Standardizing Administration

Standardizing test administration in terms of equipment and environment is relatively easy in smaller scale studies where subjects come to central locations for testing—for example, all can be tested on the same walking course. The NHANES provides a standardized environment and clinical evaluators in a national survey but at significant cost in terms of data collection time and resources. Studies like the Established Populations for Epidemiologic Studies of the Elderly (Guralnik et al., 1994) and the WHAS (Guralnik et al., 1995) represent pioneering efforts to administer physical performance-based assessments in home environments using lay interviewers. Such measures have become more common in surveys—the Health and Retirement Survey implemented physical performance tests in 2004 that are repeated on a four-year cycle.

Standardizing use of equipment and administration protocols for NHATS involves (1) explicit directions to interviewers in the NHATS Activities Booklet for both describing and demonstrating each activity to the respondent, (2) gaining proficiency through practice in use of the equipment, (3) formal certification of administration techniques at training for the first wave of data collection, and (4) a Web-based recertification midway through the data collection period to guard against administrator "drift" away from standard protocol. Standardizing the walking course and the chair stands are especially challenging. Setting up the walking course requires a space in or near (e.g., the hall of an assisted living facility) the home that is 16 feet long and three feet wide; walking speed is timed over three meters of this distance with about one meter of

additional space needed at each end, before the start and after the finish. The space has to be cleared of furniture and cannot be an irregular surface or cross the edge of a rug. The chair stand requires that interviewers identify a chair with a hard back and no arms that can be positioned against a wall. The height between the seat edge and floor is measured and recorded.

Table 2. Exclusions for Attempting Sensory, Physical, & Cognitive Capacity Assessments

ASSESSMENT	Questions to Identify Persons Excluded from Attempting Assessments[1]
Sensory Capacity	None
Physical Capacity	
Grip Strength	In last 3 months, surgery or serious injury to both sides (left and right) for hands or wrists? In last 3 months, surgery or serious injury to both sides (left and right) for arms or shoulders? Current flare-up of pain to both sides (left and right) for hands or wrists?
Chair Stands	In last 3 months, surgery or serious injury to both hips, including hip replacement surgery? If person always uses mobility device to get out of bed or always has help to get out of bed ask: Able to get up out of chair by yourself and without mobility devices (if used)?
Balance Stands	If person always uses mobility device to get out of bed or always has help to get out of bed ask: Able to stand without holding onto someone or something?
Walking	Exclude if earlier questions indicate sample person used wheel chair or scooter **every time** to get around home or building Able to walk a short distance in room by him/herself (using mobility device if needed)?
Peak Air Flow	None
Cognitive Capacity	None

[1]Administered as questions in the CAPI instrument.

Reasons for Not Conducting Tests

An important consideration in interpreting the results of these tests has to do with which individuals do not perform them and why. Understanding the difference among persons excluded from attempting the tests, those who do not do the tests because of concerns about safety, and those who do not do the tests for other nonhealth reasons (e.g., insufficient room to conduct the walking test or refusal) is critical to analysts. Protocols for making these distinctions are not well established. Considerable attention to distinguishing among reasons for missing physical performance data has been undertaken for NHATS.

Exclusions. A series of questions has been developed for use in determining who should not be asked to attempt specific performance assessments. These are based on clinical expertise and are included in the CAPI instrument. As shown in Table 2, exclusions are tailored to activities and include recent surgery, pain, and inability to stand or walk a short distance. On grip strength, for example, if a respondent is right-handed and has had surgery on that hand in the last three months, the test would be performed with the left hand. Only in the case of surgery or a current flare-up of pain in both hands would someone be excluded from attempting the test. There are no exclusions for peak air flow nor for administering the sensory capacity questions or the cognitive assessments.

Even when a proxy interview is conducted, we ask the exclusion questions and give sample persons the opportunity to attempt the physical performance assessments. Similarly, for cognitive assessments, in the case of proxy interviews, we ask the proxy whether the sample person could try to answer some questions about memory. If the answer is "yes," we attempt to administer the cognitive assessments to the sample person.

Safety concerns. After the interviewer demonstrates each physical performance activity, she asks the respondent, "Do you think it would be safe to try this?" If the respondent or a proxy who is involved in the

interview indicates feeling unsafe, this can be selected from the precoded reasons for not attempting a test, and the interviewer moves on to the next test. In addition, the interviewer may feel the test cannot be done safely and can indicate that the test was not done because the interviewer felt unsafe for the sample person or the sample person was unsteady with support.

Other reasons test was not conducted. Precoded reasons for not attempting a test are standardized across assessments with minor exceptions. The walking course and chair stands include response categories that allow interviewers to indicate "no appropriate space/no appropriate chair" as reasons these assessments were not attempted. Another precoded reason for not attempting a test included for all assessments is that the respondent is "unable to understand directions" after the interviewer has explained and demonstrated the activity. Finally, an "other—specify" option is provided so interviewers can indicate circumstances other than those covered in the precoded reasons for not attempting an assessment.

Respondent Reactions

We avoid the words "test" and "performance" as much as possible in connection with performance-based assessments; for example, the booklet interviewers use to record results is labeled the NHATS Activities Booklet. In introducing the physical performance assessments, respondents are told they will be asked "to perform a few simple movements, that is, to move your body in different ways." The cognitive assessments are introduced with the statement "The next few questions are about people's memory and ability to think about things." Nonetheless, in connection with these types of activities—remembering a list of words, performing timed repeated rapid chair stands—respondents sometimes ask about how their performance ranks with others. For the Stroop test, a fireworks display at the end of the test is intended as positive feedback for completing the test. Our experience from the NHATS Validation Study and pretest is that interviewers are likely to be asked by respondents how their performance measures up for both physical and cognitive capacity assessments, and they need training on how to respond to these requests.

DATA ON ADMINISTRATION: EXPERIENCE WITH PHYSICAL PERFORMANCE-BASED ASSESSMENTS & THE COMPUTERIZED STROOP TEST

Tables 3 through 5 provide data regarding who did and did not attempt the physical performance-based activities. Data combine a sample chosen for the NHATS Validation Study (n = 326) selected purposefully to include persons in residential care facilities and persons receiving help with self-care activities and from a pretest (n = 120) that employed a sample design that will be used for the national baseline (e.g., age-stratified). Characteristics of this total sample (n = 446) were 38% age 80 or older, 79% in excellent/very good/good self-rated health, 83% with excellent/very good/good self-reported memory, and 13% in residential care (other than nursing homes).

Overall, a high percentage did the physical performance activities: 93% for the easiest balance test (side-by-side), 89% for walking speed, 86% for single chair stands, 89% for grip strength, and 97% for peak air flow (Table 3). The proportions excluded from attempting a test were below 5% except for grip strength. For both grip strength and peak air flow, an analysis of correlations between measures of average and highest scores (by age and gender) based on two versus three trials were extremely high (.98) (data not shown), leading to a decision to conduct two trials of each in the national data collection.

Table 3. NHATS Physical Capacity Assessments (*n* = 446)

ACTIVITY	DID ACTIVITY[1]	ACTIVITY NOT DONE			
		Exclusions	Did Not Complete Prior Activity[2]	Not Attempted for Safety Reasons[3]	Not Attempted for Other Reasons[4]
Balance Stands					
Side by side	93%	3%	—	3%	1%
Semi-tandem	87%	3%	2%	6%	2%
Full tandem	74%	3%	10%	11%	2%
One leg, eyes open	47%	3%	30%	17%	3%
One leg, eyes closed	11%	3%	65%	18%	3%
Walking Speed					
1st trial	89%	3%	—	1%	7%
2nd trial	89%	3%	—	1%	7%
Chair Stands					
Single	86%	4%	—	6%	4%
Repeated rapid	78%	4%	2%	8%	7%
Grip Strength					
1st trial	89%	8%	—	1%	2%
2nd trial	89%	9%	—	1%	2%
3rd trial	89%	9%	—	1%	2%
Peak Air Flow					
1st trial	97%	—	—	2%	2%
2nd trial	97%	—	—	2%	2%
3rd trial	96%	—	—	2%	2%

[1]Includes sample persons (SP) who completed the activity and sample persons who tried the activity but did not complete it.
[2]For example, an SP who tried a side-by-side balance stand but could not complete the activity was not asked to try the semi-tandem balance stand or any of the other balance stands.
[3]Safety reasons include when an SP, proxy, or interviewer felt the activity would be unsafe for the SP or the SP was unsteady with support.
[4]Other reasons included SP did not understand the instructions, there was not enough room to attempt the walking course, no suitable chair for chair stands, and refusals.
SOURCE: Data from Validation Study in spring 2010 (*n* = 326) and pretest in winter 2010 (*n* = 120).

For balance stands and chair stands, as sample persons progressed to harder activities, the percentage performing the activity dropped, by design, since persons who were unable to complete an easier activity (e.g., hold a side-by-side stand for ten seconds) were not asked to do the next harder one. The most difficult balance stand—standing on one leg with eyes closed for 30 seconds—which is intended as a high functioning test—was attempted by only 11%; 65% were not asked to attempt this activity based on failing to complete easier balance tests. Similarly, while 86% did the single chair stand, the percentage doing the more difficult repeated rapid chair stands was 78%. The tests most often not attempted for safety reasons were the more difficult balance stands and the chair stands.

Tables 4 and 5 show physical performance activities by age, self-reported health status, self-reported memory, and whether the sample person was in a residential care facility. In terms of balance stands (Table 4), among those 80 or older, 89% attempted the side-by-side stand. Attempts dropped as the activity became more difficult, but 25% attempted the "one leg, eyes open stand." There were significant differences by age in attempting all of the stands from the easiest—side by side (attempted by 96% of 65–79 year-olds and 89% of persons 80+)—to the most difficult—one leg, eyes closed (attempted by 18% of 65–79 year-olds and 1% of persons 80+). Persons in fair/poor self-rated health were less likely to do all of the balance stands than those in better health, with the exception of the easiest stand (side by side). There were differences by self-rated memory for only two of the five stands (full tandem and one leg, eyes closed). Persons in residential care facilities were less likely to do all of the balance stands compared to those in community living settings.

The primary reasons for not doing a balance test were inability to do the prior easier test and safety concerns of the sample person, proxy, or interviewer (these are coded separately but combined as "Safety" in Table 4). Not surprisingly, as the tests become more difficult, fewer were eligible and safety concerns were more often indicated. For example, among persons 80+, 59% tried holding the full tandem stand for ten seconds. Only 25% tried the one leg stand with eyes open because 41% were unsuccessful in completing the full tandem stand (or prior balance tests), and safety concerns were expressed for another 22%.

Percentages attempting the other physical performance tests also were high (Table 5). There were no differences by age, self-rated health or memory, or residence in doing the walking speed test. Significant differences were observed for all of these characteristics for the single and repeated rapid chair stands, however. Percentages attempting the repeated rapid chair stands were lower than for the single chair stand (inability to do the single stand precluded attempting the repeated rapid stands). Nonetheless, over half of persons in fair/poor self-rated health or in a residential care facility attempted this test, which requires doing five quick repetitions of standing and sitting with arms folded across one's chest. For grip strength and peak air flow, there were no significant differences in attempting these tests with the exception of self-rated health. Percentages attempting the grip strength test were above 85% for all groups except those in fair/poor health and those in residential care facilities (where 83% attempted the test). Over 90% of all persons attempted the peak air flow test.

Table 6 provides pretest data (n = 120) on the computerized Stroop CFI. Only pretest data are shown because changes were made between the Validation Study and the pretest in administration of the practice that precedes the test. The interviewer administered the Stroop CFI by describing the "game," showing the respondent how to use the handheld keypad to register answers (press red-, blue-, and green-colored buttons), and initiating a short practice that repeats instructions when individuals miss two consecutive items. The interviewer confirms that the participant understands the instructions before starting the test. The "easy" and "difficult" conditions (described earlier) appear in random order on the screen every two seconds. Most study participants were willing to try the Stroop even though it was placed at the end of the interview. In the pretest sample, only a small percentage (9%) of persons did not attempt the Stroop. These included individuals who were blind, had severe cognitive impairment, or who refused.

Table 6 shows accuracy on the "easy" and "difficult" conditions on the Stroop CFI. Accuracy is important in determining whether participants comprehended each condition and provided enough correct answers beyond chance to calculate the Stroop effect (average speed of correct responses, or reaction time). The task is feasible across a range of cognitive ability levels, and information on ability to complete the two conditions is informative. Overall, 61% of pretest participants were able to accurately complete both the easy and difficult conditions. About 15% were unable to complete both conditions, and another 15% were able to complete the easy but not the difficult condition. The performance of the former group is indicative of global cognitive impairment; the latter group may be at risk for cognitive impairment given their worse performance in response to increased demands on attention. Ability to accurately complete both conditions varied by age and memory (ten-word recall). Differences by self-rated health and education were not significant.

Table 4. NHATS Balance Tests, by Age, Self-Reported Health & Memory, & Residence in a Facility (*n* = 446)

	AGE		SELF-REPORTED HEALTH STATUS		SELF-REPORTED MEMORY		FACILITY RESIDENT	
	65–79	80+	Excellent/ Very Good/ Good	Fair/Poor	Excellent/ Very Good/ Good	Fair/Poor	Yes	No
Total (*n*)	276	170	352	94	369	67	58	388
SIDE-BY-SIDE STANDS								
Did activity[1]	96%	89%*	94%	89%	94%	94%	79%	95%*
Did not do:								
Exclusion[2]	0%	8%	2%	6%	2%	1%	9%	2%
Prior test not done	—	—	—	—	—	—	—	—
Safety[3]	3%	2%	2%	4%	2%	4%	9%	2%
Other reason[4]	1%	1%	1%	0%	1%	0%	3%	1%
SEMI-TANDEM STANDS								
Did activity[1]	91%	81%*	89%	78%*	89%	82%	62%	91%*
Did not do:								
Exclusion[2]	0%	8%	2%	6%	2%	1%	9%	2%
Prior test not done	1%	4%	2%	3%	2%	3%	7%	2%
Safety[3]	6%	6%	4%	13%	5%	12%	16%	5%
Other reason[4]	1%	2%	2%	0%	2%	1%	7%	1%
FULL TANDEM STANDS								
Did activity[1]	84%	59%*	79%	59%*	79%	58%*	38%	80%*
Did not do:								
Exclusion[2]	0%	8%	2%	6%	2%	1%	9%	2%
Prior test not done	6%	15%	8%	17%	8%	19%	24%	7%
Safety[3]	8%	15%	9%	18%	10%	19%	22%	9%
Other reason[4]	1%	3%	2%	0%	2%	1%	7%	1%
ONE LEG EYES OPEN STAND								
Did activity[1]	60%	25%*	51%	29%*	49%	37%	12%	52%*
Did not do:								
Exclusion[2]	0%	8%	2%	6%	2%	1%	9%	2%
Prior test not done	24%	41%	28%	41%	30%	34%	47%	28%
Safety[3]	14%	22%	15%	23%	16%	25%	26%	16%
Other reason[4]	2%	4%	3%	0%	3%	1%	7%	2%
ONE LEG EYES CLOSED STAND								
Did activity[1]	18%	1%*	13%	5%*	13%	3%*	2%	13%*
Did not do:								
Exclusion[2]	0%	8%	2%	6%	2%	1%	9%	2%
Prior test not done	64%	65%	65%	65%	65%	69%	57%	66%
Safety[3]	15%	22%	16%	23%	17%	25%	26%	17%
Other reason[4]	2%	4%	3%	0%	3%	1%	7%	2%

[1]Includes sample persons (SP) who completed the activity and sample persons who tried the activity but did not complete it.
[2]For example, an SP who tried a side-by-side balance stand but could not complete the activity was not asked to try the semi-tandem balance stand or any of the other balance stands.
[3]Safety reasons include when an SP, proxy, or interviewer felt the activity would be unsafe for the SP or the SP was unsteady with support.
[4]Other reasons included SP did not understand the instructions, there was not enough room to attempt the walking course, no suitable chair for chair stands, and refusals.
NOTE: Ten cases done by proxy respondent are missing on the self-reported memory measure.
***Significant difference between those who did and did not (all reasons) do activity at $p < .05$.
SOURCE: Data from Validation Study in spring 2010 (*n* = 326) and pretest in winter 2010 (*n* = 120).

Table 5. NHATS Other Physical Capacity Assessments, by Age, Self-Reported Health & Memory, & Residence in a Facility (*n* = 446)

	AGE		SELF-REPORTED HEALTH STATUS		SELF-REPORTED MEMORY		FACILITY RESIDENT	
	65–79	80+	Excellent/ Very Good/ Good	Fair/Poor	Excellent/ Very Good/ Good	Fair/Poor	Yes	No
Total (*n*)	276	170	352	94	369	67	58	388
WALKING SPEED (1st Test)								
Did activity[1]	91%	86%	91%	84%	91%	90%	90%	89%
Did not do:								
Exclusion[2]	1%	5%	2%	5%	2%	1%	7%	2%
Prior test not done	—	—	—	—	—	—	—	—
Safety[3]	1%	2%	1%	2%	1%	1%	2%	1%
Other reason[4]	7%	8%	7%	9%	7%	7%	2%	8%
SINGLE CHAIR STANDS								
Did activity[1]	91%	79%*	89%	76%*	89%	78%*	66%	89%*
Did not do:								
Exclusion[2]	0%	9%	3%	7%	3%	0%	9%	3%
Prior test not done	—	—	—	—	—	—	—	—
Safety[3]	5%	6%	5%	11%	5%	13%	14%	5%
Other reason[4]	4%	4%	3%	6%	3%	9%	12%	3%
REPEATED RAPID CHAIR STANDS								
Did activity[1]	84%	69%*	82%	66%*	82%	69%*	53%	82%*
Did not do:								
Exclusion[2]	1%	9%	3%	9%	3%	0%	9%	3%
Prior test not done	6%	11%	7%	12%	7%	15%	14%	7%
Safety[3]	1%	4%	2%	3%	2%	3%	3%	2%
Other reason[4]	7%	7%	6%	11%	6%	13%	21%	5%
GRIP STRENGTH (1st Test)								
Did activity[1]	91%	86%	91%	83%*	91%	90%	83%	90%
Did not do:								
Exclusion[2]	7%	11%	7%	14%	8%	10%	14%	7%
Prior test not done	—	—	—	—	—	—	—	—
Safety[3]	1%	1%	1%	1%	1%	0%	2%	1%
Other reason[4]	1%	2%	1%	2%	1%	0%	2%	2%
PEAK AIR FLOW (1st Test)								
Did activity[1]	97%	96%	98%	93%*	97%	100%	97%	97%
Did not do:								
Exclusion[2]	0%	0%	0%	0%	0%	0%	0%	0%
Prior test not done	—	—	—	—	—	—	—	—
Safety[3]	2%	1%	1%	4%	2%	0%	2%	2%
Other reason[4]	1%	3%	1%	3%	1%	0%	2%	2%

[1]Includes sample persons (SP) who completed the activity and sample persons who tried the activity but did not complete it.

[2]For example, an SP who tried a side-by-side balance stand but could not complete the activity was not asked to try the semi-tandem balance stand or any of the other balance stands.

[3]Safety reasons include when an SP, proxy, or interviewer felt the activity would be unsafe for the SP or the SP was unsteady with support.

[4]Other reasons included SP did not understand the instructions, there was not enough room to attempt the walking course, no suitable chair for chair stands, and refusals.

*****Significant difference in who did (vs. did not for all reasons) activity at $p < .05$.

NOTE: Ten cases done by proxy respondent are missing on the self-reported memory measure.

SOURCE: Data from Validation Study in spring 2010 (*n* = 326) and pretest in winter 2010 (*n* = 120).

Table 6. Levels of Ability to Perform the Easy & Difficult Components of the Stroop Cognitive Frailty Instrument (CFI) in the NHATS Pilot & Their Cognitive & Demographic Characteristics (*n* = 120)

VARIABLE	Missing[1]	Unable to Complete Easy & Difficult	Unable to Complete Difficult	Able to Complete Both
Total, % (*n*)	9% (11)	15% (18)	15%(18)	61% (73)
Age, Mean [SD]	86.7 [9.4]**	81 [8.2]*	77.9 [7.5]	75.4 [7.6]
Self-Rated Health				
Excellent/Very good/Good	45% (5)	61% (11)	89% (16)	79% (58)
Fair/Poor	54% (6)	39% (7)	11% (2)	21% (15)
Education				
1–12 years (no high school diploma)	30% (3)	28% (5)	11% (2)	19% (14)
High school graduate	30% (3)	33% (6)	28% (5)	29% (21)
Some college	30% (2)	28% (5)	39% (7)	23% (17)
College graduate, graduate degree	20% (2)	11% (2)	22% (4)	29% (21)
10-Word Recall Immediate, Mean [SD]	1.5 [1.7]**	3.1 [1.7]**	4.4 [1.3]	5.0 [1.9]
10-Word Recall Delayed, Mean [SD]	0.8 [1.4]**	1.5 [1.5]**	2.6 [1.8]*	3.8 [2.0]

[1]Reasons include blindness, refusal, severe cognitive impairment.

* $p < .05$, ** $p < .001$; all *p*-values calculated using "Able to Complete Both" as the reference category; ANOVA tests used for continuous variables, Pearson's chi-square test for discrete variables.

NOTE: Missing data: one case education.

SOURCE: Data from pretest in winter 2010.

CONCLUSION

Capacity measures based on performance assessments of physical and cognitive function play a distinct role in the conceptual framework of disability that has guided development of NHATS and will make it possible to better understand individual trajectories and the role of accommodations and the environment in doing activities when capacity declines. In addition, prior studies have confirmed the empirical value of performance-based physical and cognitive assessments in predicting health outcomes.

The measures selected for NHATS represent those that tap into major areas of physical (lower and upper extremity) and cognitive (memory, orientation) capacity, can be used to create constructs such as the Short Physical Performance Battery that have gained widespread use in the scientific literature, and provide opportunities for harmonization with other large population-based surveys of older people. NHATS also has included tests that allow identification of high-functioning people and can be used to observe small changes over time in these individuals. Persons who attempted the one-leg balance stands and those who met accuracy thresholds for the Stroop test were in this high-functioning segment of the older population. Membership in this group was associated with better self-reported health and memory (and for the Stroop test, higher performance on two memory tests).

Performance-based assessments of physical and cognitive capacity are increasingly common in population-based surveys, and NHATS represents an important step forward in this evolution. Drawing on earlier studies of older people, the NHATS protocol is aimed at standardizing administration of these tests by lay interviewers in home environments for annual administration in a longitudinal study. A particular focus has been standardizing and accounting for reasons that tests are *not* done—health-related exclusions, inability to complete easier tests, and safety. Missing data on performance tests is often substantial but also informative and useful analytically if the various reasons for missingness are carefully documented.

As a new survey, NHATS has been able to give consideration to the implications of doing these types of assessments from the outset, starting with interviewer recruitment and training. Experience from the Validation Study and Pretest have led to refinements of these procedures (e.g., use of videos in recruitment; certification procedures in training) and to the NHATS Activities Booklet. Training materials and data collection instruments will be available later this year at www.nhats.org.

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The Development and Evaluation of Disability Measures Using a Mixed-Method Approach[1]

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INTRODUCTION

The assessment of many contemporary health survey variables is best accomplished with a dynamic question development and evaluation strategy. This is particularly true of health survey items that focus on complex concepts such as disability and functioning. It is also important when evaluating the quality and performance of survey questions across cultural settings and national boundaries (Harkness et al., 2010). Several methods are available to researchers for use in the development of survey questions; however, each method has its own strengths and weaknesses. This paper presents a mixed-method approach that combined cognitive interviewing and field test methodology to evaluate a set of disability questions for use on health surveys internationally.

In developing survey questions, a notable challenge is to account for the numerous ways that respondents across differing cultures, languages, and socioeconomic conditions might interpret and process those questions. The challenge is further heightened when the construct to be measured is a complex concept. The concept of disability, for example, is complex because it involves numerous and varied meanings, attitudes, and types of experiences across individuals and cultural subpopulations. Because social context and cultural circumstances inform the way respondents interpret, consider, and ultimately respond to questions, these differences can lead to systematic measurement error in survey data. Rather than interpreting differences in survey estimates as response process bias, they can be wrongfully construed as real differences in the phenomena of study.

To ensure comparability of measures across sociocultural groups, it is necessary to understand the degree of interpretive and response process variation across groups. Survey questions can then be revised to account for the variation. For this reason, question evaluation studies, particularly those intended for heterogeneous populations, should address the following line of inquiry:

- How do respondents understand each survey question?
- Do respondents understand the questions differently?
- Does each of the questions mean the same in all the languages in which it is asked?
- Does each question mean the same in all of the cultures in which it is asked?
- In processing each question, do all respondents recall information and construct an answer with similar processes?
- What other subgroups (e.g. gender, age, socioeconomic status, health or disability status) should be considered for comparability?

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[1] This paper was the result of collaboration between the United Nations and Social Commission for Asia and the Pacific (UNESCAP) and the Washington Group on Disability Statistics. We wish to acknowledge the efforts of all of the countries that have participated in this project.

[2] The findings and conclusions in this report are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

- To what extent are survey data elicited from each question a true representation of the intended phenomena of study?
- In what ways is the picture distorted because the questions do not accurately capture the intended construct?

In successfully addressing these issues, a question evaluation study can provide rich understanding of how questions perform. In turn, this understanding allows designers the opportunity to improve measurement validity and increase equivalence or, at least, to provide documentation regarding the appropriate interpretation of the resulting data.

METHODS[3]

In collaboration with the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP), the Washington Group developed a set of disability questions intended as components of population surveys, as supplements to surveys, or as the core of a disability survey. The WG/UNESCAP question evaluation project is based on the line of inquiry outlined above and is reflected in the project's mixed-method design. The specific objectives of the cognitive interviewing component were to identify the following interpretive patterns: (1) respondents' interpretations of the specific questions, (2) calculation and other processes used by respondents to formulate their answers to the questions, and (3) types of response error problems (Miller, 2011). Findings from the cognitive interviewing component established hypotheses to be examined in the second component—the field test. While the cognitive interviewing study determined the specific patterns of interpretation, the field test was used to understand the extent to which those patterns existed in a larger, representative sample. More specifically, it was used to examine the extent of problematic patterns, such as unintended interpretations and whether they occurred in particular subgroups.

The WG/UNESCAP project included cognitive interviewing and field testing of the extended question set in six countries. A total of 155 cognitive interviews were completed in Cambodia, Canada, Kazakhstan, Maldives, Mongolia, Philippines, South Africa, Sri Lanka, and the United States.

Each country first conducted approximately 20 semistructured qualitative cognitive interviews using a purposive sample. Samples were broadly reflective of different disability statuses (types/severities), ages, gender, and socioeconomic status. The interview was semistructured, consisting of the test and probe questions to elicit narrative information from the respondent about their answers. The protocol was written in English; countries conducting interviews in other languages were responsible for translating the protocol.

Interviewers were instructed to keep detailed notes during interviews so they would be able to write up a thorough narrative regarding how each respondent answered each of the test questions. An online data entry application (Q-Notes) was developed for interviewers to record their notes for each question and each interview. Methodologists at the National Center for Health Statistics then were able to review the quality of the cognitive interview data and provide feedback for improvement. The application also allowed for a fast, in-depth analysis of the interviews.

The methodology of field tests is quite diverse (Converse & Presser, 1986). Field tests often are viewed as pilot tests or dress rehearsals to ensure that survey processes and procedures are worked out prior to full-

[3] Detailed methodological information regarding the WG/UNESCAP project can be found at www.unescap.org/stat/disability/analysis/

scale implementation. This provides relatively minimal information with respect to question evaluation—for example, information about the distribution of variables and the level of item nonresponse. Field tests also may include embedded experiments or other methodological studies (e.g., behavior coding, debriefing studies). Our approach was to improve the field test with information from the cognitive interviews by supplementing the field test questionnaire with structured probe questions. That is, analysis of the cognitive interviews revealed both problematic and nonproblematic interpretive patterns, and additional questions were added to the field test questionnaire to capture the extent to which those various interpretive patterns existed. This provides quantitative evidence about the presence and extent of the various interpretive patterns in the different countries that participated in the field test. The field test was conducted in Cambodia, Kazakhstan, Maldives, Mongolia, the Philippines, and Sri Lanka. Each country participating in the field test conducted approximately 1,000 standardized survey interviews drawn from probability samples within specific areas of each country.[4] Resulting survey data from the follow-up probe questions were used to examine the extent of valid and nonvalid interpretive patterns. We present several descriptive analyses below that illustrate the presence of these patterns and how they related to the responses to one of the survey questions.

RESULTS

We illustrate this approach by presenting the results about the construct of anxiety from the functioning domain of affect.[5] Affect is the domain dealing with emotional functioning and includes depression and anxiety. These two domains are important to measure as they provide some indications of emotional or psychiatric disability. Symptoms of depression and anxiety can be common occurrences in most people's lives. However, the question developers' intent was to be able to identify depression and anxiety that goes beyond what is considered "normal." The cognitive interviews were designed to determine if the questions developed appropriately captured more severe levels of depression and anxiety.

Questions were designed to capture two specific aspects of anxiety: frequency and intensity. Analyzed together, the intent of the questions was to place respondents along a severity continuum comprised of various dimensions of anxiety (i.e., frequency and intensity).

Cognitive Interviewing Results

The following four questions were examined in the cognitive interviews:

1. How often do you feel worried, nervous or anxious? Daily, weekly, monthly, a few times a year, or never?
2. Do you take medication for anxiety?
3. Thinking about the last time you felt anxious, how would you describe the level of anxiety? Mild, moderate, or severe?
4. Thinking about the last time you felt anxious, was the anxiety worse than usual, better than usual, or about the same as usual?

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[4] The sampling designs vary by country and were not intended to produce nationally representative estimates. Hence, sampling design information and weights were not included in the data files. Most countries conducted cluster or systematic samples of key populations (e.g., urban and rural populations). Significance tests in this paper assume simple random sampling and may underestimate the variance in some countries.

[5] Results from other functioning domains can be found at www.unescap.org/stat/disability/analysis/

In answering these questions, respondents considered a range of feelings and experiences they recognized as anxiety—or rather, what they believed the question was asking in terms of being "worried, nervous or anxious." For the most part, the feelings and experiences considered by respondents were consistent with various aspects of the intended concept of anxiety, with the following range of patterns reported.

1. Clinical anxiety, whereby respondents described being diagnosed by a medical professional.
2. Elements of depression, whereby respondents spoke about being overly sad, wanting to stay in bed, or being unable to perform daily activities, and
3. Stress-related worry, which respondents connected to work (e.g., heavy workloads, deadlines, performances), family or relationship problems, crime, or concerns about their economic future and physical well-being.

One problematic pattern, however, was reported by a handful of respondents who spoke about their anxiety as being a positive characteristic. These respondents, it appears, interpreted the question as asking about being excited, energetic, or looking forward to the future. For example, one U.S. narrative states:

> *"Well it depends on what it is I got to do. Because I kind of get like hyped up when I know I've got to get something done by a certain time. I put the pressure on me to get it done by that certain deadline. That's just me." I asked him what he meant by hyped up and he stated "I get like an adrenaline rush. I make myself get it done quick but whenever I'm doing it in a quick way I'm often doing it in a safe, productive way to where I don't get myself hurt or anybody else hurt." I asked him if he feels nervous or worried when this is happening and he said "no, just calm, relaxed, just know what I need to get done." He described what he was feeling as an energy boost, but not worried or nervous. I asked him about the last time this happened, he described going to school, and making sure he got there on time.*

This particular interpretation was clearly used by a small minority of respondents and was only found in the United States and Canada. It is possible, however, that this interpretation did exist in other regions that were not sufficiently detailed in the narratives. The field test was used to determine the extent of this pattern and whether it exists in particular subgroups.

Field Test Results

The final questions used on the field test and relevant to this paper are shown in the appendix. The core questions about the frequency and intensity of anxiety were included, as was the medication question. Also included were respondent probe questions that were developed from the patterns identified in the cognitive interviews and an impact question that was used to understand the amount of limitation respondents face in their daily activities as a result of anxiety. We first report the descriptive findings by country.

Overall, nearly half of the respondents (47.3%) in the field test reported that they never felt worried, nervous, or anxious. One in four reported that they experience these feelings a few times a year. One in ten indicated they experience anxiety monthly. Nearly one in five (19.1%) respondents reported that they experience anxiety either weekly or daily. As Table 1 shows, the frequency of anxiety reported varies significantly by country. For example, almost one third (30.9%) of respondents in Kazakhstan reported that they experience anxiety weekly or daily. Similarly, one in four (26.0%) respondents from Mongolia reported that they experience anxiety at least weekly. At the other end of the spectrum, only about 10% of respondents from Sri Lanka and the Philippines reported experiencing anxiety weekly or daily. In fact, 78.4% of respondents from Sri Lanka reported that they never experience anxiety.

As shown in Table 2, almost one in five (19.2%) respondents reported that they experienced a lot of anxiety the last time they had these feelings. The intensity of anxiety reported varies significantly by country. One third (34.8%) of respondents from Sri Lanka and 40.9% of respondents from Maldives described the level of these feelings as "a lot." The level of these feelings is much lower in the other countries. No more than 16.9% in any of the remaining countries described the level of their feelings as "a lot," and only 7.2% in the Philippines described the level of these feelings as "a lot."

Table 3 demonstrates the association between anxiety frequency and intensity, showing the percentage of respondents who report "a little" intensity by frequency for each country. In general, respondents reporting lower levels of intensity also report lower frequencies of these feelings.

The field test included follow-up probe questions based on patterns identified in the cognitive interviews. The percentage reporting that each statement describes his or her feelings by country is shown in Table 4.

Table 1. Frequency of Anxiety, by Country

FREQUENCY	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	ALL COUNTRIES
Never	31.9%	39.7%	78.4%	46.6%	35.4%	54.3%	47.3%
Few times a year	22.9	28.7	7.5	27.3	25.6	25.3	23.0
Monthly	13.6	14.5	2.7	5.7	12.8	10.8	10.1
Weekly	17.6	9.2	2.1	9.0	12.4	7.7	9.7
Daily	13.3	7.4	8.1	11.0	13.6	1.7	9.3
Refused	0.2	0.0	0.1	0.1	0.1	0.0	0.1
Don't know	0.5	0.5	1.1	0.4	0.3	0.2	0.5
N	(1,000)	(1,008)	(1,000)	(1,013)	(1,222)	(1,066)	(6,309)

Chi-square = 817.34, 20 df, $p < .05$.

NOTE: Refused and Don't know categories excluded when calculating chi-square statistic.

Table 2. Intensity of Anxiety, by Country

INTENSITY	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	ALL COUNTRIES
A little	64.0%	62.7%	54.4%	39.4%	65.6%	83.5%	62.4%
Closer to a little	4.9	2.0	2.0	1.7	4.3	1.4	3.0
In between	10.2	18.6	6.4	15.1	6.8	6.8	11.0
Closer to a lot	6.7	2.2	2.0	1.1	5.1	0.4	3.3
A lot	12.9	14.1	34.8	40.9	16.9	7.2	19.2
Refused	0.2	0.0	0.0	0.0	0.3	0.0	0.1
Don't know	1.2	0.5	0.5	1.9	1.0	0.6	1.0
N	(675)	(603)	(204)	(536)	(785)	(486)	(3,289)

Chi-square = 443.68, 20 df, $p < .05$.

NOTE: Refused and Don't know categories excluded when calculating chi-square statistic.

Table 3. Percentage of Respondents Reporting "a Little" Intensity, by Frequency & Country

Frequency	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	ALL COUNTRIES
Few times a year	81.3%	82.3%	60.0%	52.2%	77.5%	91.5%	76.1%
Monthly	68.2	59.6	55.6	33.3	79.5	75.4	66.6
Weekly	55.8	36.6	61.9	36.3	56.7	80.5	53.7
Daily	45.5	27.0	47.5	17.3	42.3	44.4	37.1

Table 4. Description of Anxiety, by Country

DESCRIPTION OF FEELINGS	COUNTRY						ALL
	Kazakhstan	Cambodia	Sri Lanka	Maldives	Mongolia	Philippines	
RESPONSE ERROR							
Positive	50.3%	47.8%	12.6%	51.7%	82.5%	32.4%	53.0%
Normal	81.5	71.3	75.4	86.7	85.7	81.2	81.1
STRESS-RELATED							
Work	34.1	63.6	25.1	34.8	54.7	37.3	44.5
Economic	49.4	67.4	51.3	32.6	69.4	42.7	53.9
IMPAIRMENT, LIMITATION, PATHOLOGY							
Chest hurts	21.4	72.3	30.9	37.0	50.6	20.3	40.6
Interfere	52.2	65.0	85.4	54.8	72.8	33.5	59.1
Clinical	11.8	16.8	3.0	28.4	18.6	11.5	16.5

NOTE: Chi-square p <.05 for all rows in the table.

Table 5. Joint Distribution of Anxiety Frequency & Intensity

INTENSITY	FREQUENCY				
	A few times a year	Monthly	Weekly	Daily	DK/REF
A little	1,087	423	328	214	1
Closer to a little	35	25	27	12	0
In between	122	85	95	59	0
Closer to a lot	22	16	39	33	0
A lot	163	86	122	259	0
DK/REF	22	3	3	7	1

NOTE: Polychoric correlation = .42.

The statements can be roughly divided into three groupings. The first describes feelings of anxiety that are more or less normative or even have a positive effect. One might be concerned about response error if a respondent were to base their response completely on these considerations. The second grouping has to do with stress-related factors that may cause anxiety. The percentage reporting that their feelings are due to the type and amount of work they do is highest for respondents who experience feelings of anxiety either monthly or weekly. The third grouping of statements refers to more severe types of anxiety. These statements refer to impairments, limitations, or clinical diagnoses related to anxiety.

The table reveals considerable variation by country in the percentage answering positively to the statements. Of note is that Mongolia had a high number of respondents who endorsed the "positive" notion of anxiety, while very few from Sri Lanka endorsed this description. A substantial number of respondents from each country endorsed the description of the feelings being normal. Descriptions of anxiety related to economic reasons, work, or chest hurting were highest for Cambodia and Mongolia. The Maldives had the highest rate for diagnosed anxiety and Sri Lanka the lowest.

Table 5 shows the joint distribution of the anxiety frequency and intensity questions combining the data from all countries. Intuitively, the seriousness of anxiety would be lowest in the upper left corner of the table and increase as one moves towards the lower right corner of the table. In addition, the correlation between these variables (polychoric correlation = .42) demonstrates, as expected, that the intensity of anxiety increases with frequency.

The next step was to characterize within each of the cells in Table 4 how respondents answered the probe questions and impact question. Table 6 depicts the results of bivariate logistic regression models predicting the probability of a respondent being located in each cell as a function of the probe questions. The dependent variable was scored 0 if the respondent was not located in the cell of interest and 1 if they were.

The independent variables in the models included the seven patterns of anxiety from Table 4 (all scored 1 if the respondent selected the pattern; 0 if they did not) and a limitation in daily activities variable (scored 1 = a little limited to 4 = completely limited).

Table 6 illustrates how the patterns of anxiety are associated with being located in each cell in the joint distribution of frequency and intensity. Several observations can be made from this table. First, the upper left corner of the table shows that anxiety described as being related to work, chest pains, interference with life, economic issues, clinical diagnoses, and limitation in daily activities decrease the likelihood of selecting the lowest levels of frequency and intensity. In contrast, anxiety described as being related to chest pains, interference with daily life, clinical diagnoses, and limitation in daily activities generally increase the likelihood of responding at the higher levels of the frequency and intensity variables. Moreover, these variables are the most prominent when you get the highest level of the frequency and intensity variables.

Finally, we looked at how the patterns of anxiety varied by country. Tables 7a and 7b show how these patterns were related to frequency and intensity in Cambodia and the Philippines. While Table 1 indicates that the frequency of anxiety was similar in these two countries, Table 3 shows that the intensity of anxiety is generally lower in the Philippines than in Cambodia. This could be due to respondents in the two countries experiencing different levels of anxiety or it could be that the intensity question is interpreted differently in the two countries. That is, different response patterns may persist in the two countries. In fact, an examination of the two tables shows that intensity increases with the prevalence of similar types of response patterns. For example, respondents with higher levels of intensity tend to experience more interference with their lives and limitation in their daily activities. This pattern is observed in both countries and is present at nearly every level of frequency.

Table 6. Factors Influencing Different Levels of Response to the Anxiety Frequency & intensity Question

	FREQUENCY			
INTENSITY	**A few times a year**	**Monthly**	**Weekly**	**Daily**
A little	Work*** Chest hurts*** Interfere*** Economic*** Clinical*** Limited***	Clinical** Limited*** Work*** Economic**	Chest hurts*** Interfere*** Work***	Normal*** Interfere*** Limited**
Closer to a little			Economic**	
In between	Normal**	Positive** Work*** Limited**	Chest hurts*** Limited***	Interfere*** Economic** Limited***
Closer to a lot	Interfere**		Interfere** Economic*** Limited***	Chest hurts** Limited**
A lot	Work*** Economic** Normal** Chest hurts*** Interfere** Clinical***	Positive** Chest hurts*** Interfere** Clinical*** Limited***	Chest hurts*** Interfere*** Clinical*** Limited***	Positive*** Chest hurts*** Interfere*** Clinical*** Limited***

NOTE: Negative associations shown in red text. Positive associations shown in black text.
**$p < .05$, ***$p < .005$.

Table7a. Factors Influencing Different Levels of Response to the Anxiety Frequency & Intensity Question in the Philippines

	FREQUENCY			
INTENSITY	**A few times a year**	**Monthly**	**Weekly**	**Daily**
A little	Work** Chest hurts*** Interfere*** Economic*** Limited***		Work**	Interfere**
Closer to a little	Clinical**			
In between	Interfere**	Interfere**	Chest hurts** Interfere**	
Closer to a lot				
A lot	Normal** Chest hurts*** Limited**	Chest hurts** Limited***	Chest hurts** Interfere** Limited**	Limited***

Negative associations shown in red text. Positive associations shown in black text.
**$p < .05$, ***$p < .005$.

Table7b. Factors Influencing Different Levels of Response to the Anxiety Frequency & Intensity Question in Cambodia

	FREQUENCY			
INTENSITY	**A few times a year**	**Monthly**	**Weekly**	**Daily**
A little	Work** Chest hurts*** Interfere*** Limited*** Positive**	Work***		Work** Economic**
Closer to a little	Clinical**			
In between		Positive** Work** Limited**	Chest hurts**	Limited***
Closer to a lot			Limited**	
A lot	Work**	Clinical** Limited***	Limited**	Interfere**

Negative associations shown in red text. Positive associations shown in black text.
**$p < .05$, ***$p < .005$.

DISCUSSION

In this paper, we have illustrated a mixed-method approach to question evaluation that combines a qualitative method (cognitive interviewing) with quantitative methods (supplemented field test data). We utilized the qualitative nature of cognitive interviewing to understand the detailed response processes that respondents used to answer questions about physical, mental, and emotional functioning. We then used the information that we learned about the patterns of responses to develop probe questions that would help us understand the prevalence of these interpretive patterns across countries in the field test.

Overall, we feel the mixed-method approach was a powerful technique that provided valuable insight into question performance. However, as with all methods, we did encounter our share of limitations with both the cognitive interviews and field methods. First, the cognitive interviews utilized relatively inexperienced interviewers. Even though the Q-Notes application enabled feedback, the level of experience may have had some impact on the resulting data. For example, the amount of narrative recorded varied by country and question. This has an implication for the analysis of the data and identification of the resulting

response patterns. More details in the narrative might have allowed us to identify different interpretive patterns.

The field test also presented challenges. So far, the preliminary analyses presented here suggest that when used together, the anxiety frequency and intensity questions capture a meaningful gradation in this very complex concept. However, we also have found that different levels of anxiety are captured in the countries in the field test. In addition, the descriptions of anxiety as captured by the follow-up probe questions vary by country. The next step in our analysis is, therefore, to explore in more detail whether the combination of frequency and intensity produces equivalent characteristics cross-culturally.

Although there are many quantitative methods available for studying equivalence, there is little agreement on the best approach or even the definition of equivalence. Johnson (2006) describes a number of different notions of equivalence and hence different methods to establish equivalence. It is often difficult to determine which notion is the most appropriate for a given set of data. It probably differs depending on the type of data and their intended use. We will be exploring various methods for determining cross-national equivalence in the future. The successful application of mixed-methods approaches in the field of question evaluation methodology has been a perennial challenge (e.g., Presser & Blair, 1994), and the cross-cultural component of projects like this one adds another dimension to this task.

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APPENDIX. ANXIETY FIELD TEST QUESTIONS

How often do you feel worried, nervous or anxious? Daily, Weekly, Monthly, A few times a year, Never

Do you take medication for these feelings? Yes, No

Thinking about the last time you felt worried, nervous, or anxious, how would you describe the level of these feelings? A little, a lot, somewhere in between a little and a lot

Would you say this was closer to a little, closer to a lot, or exactly in the middle? Closer to a little, Closer to a lot, Exactly in the middle

Please tell me which of the following statements, in any describe your feelings. Yes, No

- My feelings are caused by the type and amount of work I do.
- Sometimes the feelings can be so intense that my chest hurts and I have trouble breathing.
- These are positive feelings that help me to accomplish goals and be productive.
- The feelings sometimes interfere with my life, and I wish that I did not have them.
- If I had more money or a better job, I would not have these feelings.
- Everybody has these feelings; they are a part of life and are normal.
- I have been told by a medical professional that I have anxiety.

How much do these feelings limit your ability to carry out daily activities? Not at all, A little, A lot, Completely

Estimating Mental Illness in an Ongoing National Survey

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I. INTRODUCTION

There has long been a need for estimates of the prevalence of mental disorders in the U.S. population. Periodic studies such as the Epidemiologic Catchment Area (ECA) study, the National Comorbidity Study (NCS), and the National Epidemiologic Survey on Alcohol and Related Conditions (NESARC) have provided important findings on the prevalence, predictors, and correlates of mental disorders, but none of these studies was designed to track trends on an annual basis or to provide state estimates.

The demand for more frequent and detailed data on mental illness increased with the passage of the 1992 ADAMHA Reorganization Act. This legislation created the Substance Abuse and Mental Health Services Administration (SAMHSA) and required the agency to develop a definition and methodology for estimating serious mental illness (SMI) among adults, by state. States were required to utilize these data in developing their plans for use of block grant funds distributed by SAMHSA. SAMHSA convened a technical advisory group (TAG) that developed a definition of SMI, published in the *Federal Register* in 1993:

> *Persons age 18 and over, who currently or at any time during the past year, have had diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within DSM-III-R that has resulted in functional impairment.…Functional impairment is defined as difficulties that substantially interfere with or limit role functioning in one or more major life activities including basic daily living skills; instrumental living skills; and functioning in social, family, and vocational/educational contexts.* (SAMHSA, 1993)

SAMHSA later published state estimates of SMI based on this definition, using the limited data that were available at the time (NCS and ECA) and a regression model that projected national data to states according to demographic characteristics (Kessler et al., 1998). However, concerns about the validity of these estimates led SAMHSA to explore other approaches for obtaining annual estimates of SMI by state.

In December 2006, SAMHSA convened a TAG meeting to solicit recommendations for mental health surveillance data collection and analysis strategies. The TAG recommended that SAMHSA's National Survey on Drug Use and Health (NSDUH) be modified to produce estimates of SMI among adults. Recognizing the limitations on the length of the NSDUH interview, the TAG suggested that the K6 psychological distress module, already included in the NSDUH, be supplemented with questions on functional impairment. The data from these short scales then would be used to estimate SMI using a statistical model based on clinical psychiatric interviews conducted on a subsample of NSDUH respondents. The K6 had already been demonstrated to be an excellent predictor of SMI in prior studies (Kessler et al., 2003). Adding impairment indicators was important for improving statistical prediction, and the TAG also felt that this would improve face validity, and consequently public acceptance of the estimates, since impairment is a component of the SMI definition.

After the TAG meeting, SAMHSA began methodological development and testing to implement these enhancements, referred to as the Mental Health Surveillance System (MHSS), to NSDUH in 2008 (Colpe et al., 2010). The next section provides an overview of the NSDUH design. Subsequent sections describe the development, implementation, and initial results of the MHSS. A final section discusses future plans for evaluating, improving, and utilizing the MHSS.

II. DESCRIPTION OF THE NSDUH

The NSDUH is the federal government's primary source of information on the nature and extent of substance use and abuse in the United States. Conducted since 1971, the survey collects data by administering questionnaires to a representative sample of about 67,500 persons in the U.S. at their place of residence. NSDUH data are used extensively by policymakers and researchers to measure the prevalence and correlates of substance use, to identify and monitor trends, and to analyze differences in substance use patterns by population subgroups.

The respondent universe is the civilian noninstitutionalized population age 12 years old or older residing within the U.S. and the District of Columbia. Persons excluded from the universe include active-duty military personnel, persons with no fixed household address (e.g., homeless and/or transient persons not in shelters), and residents of institutional group quarters, such as jails and hospitals. The eight largest states have samples of about 3,600 respondents. For the remaining 42 states and the District of Columbia, samples of about 900 persons are selected. Young people are oversampled, with one-third of the sample in each state allocated to age groups 12–17, 18–25, and 26 and older. Thus, although the sample of adults is 45,000, half of the adult sample is 18–25. At each sampled address, a five-minute screening procedure using a handheld computer lists all household members and their basic demographic data. To obtain the target sample sizes, a preprogrammed selection algorithm selects zero to two sample person(s), depending on the composition of the household.

The data are collected through computer-assisted interviewing (CAI), including audio computer-assisted self-interviewing (ACASI), on a laptop computer. The interviews average about an hour. Each respondent who completes a full interview is given a $30 cash payment. The questionnaire contains demographic items (interviewer-administered) and self-administered questions pertaining to the use of tobacco, alcohol, and illicit drugs (as well as injection drug use), perceived risks of substance use, substance dependence or abuse, arrests, treatment for substance use problems, pregnancy and health care issues, and mental health issues (SAMHSA, 2010).

III. DESIGN OF THE MENTAL HEALTH SURVEILLANCE SYSTEM (MHSS)

Based on the *Federal Register* definition, SAMHSA established an operational definition of SMI among adults: at least one DSM-IV disorder, other than developmental or substance-use disorder, in the past 12 months that resulted in serious impairment. Serious impairment was determined to be equivalent to a DSM-IV Axis V Global Assessment of Functioning (GAF) score of less than or equal to 50.

Questionnaires

In consultation with the TAG, two candidate impairment scales were selected and modified for use in the 2008 NSDUH. They are the World Health Organization Disability Assessment Scale [WHODAS] (Rehm et al., 1999) and the Sheehan Disability Scale [SDS] (Leon, Olfson, Portera, Farber, & Sheehan, 1997).

The WHODAS consists of a series of 16 questions used for assessing disturbances in social adjustment and behavior. Because of the length of the WHODAS, an IRT analysis was done to see if a reduced set of items would be sufficient for measuring impairment. This resulted in an abridged set of eight WHODAS items used in NSDUH (Novak, Colpe, Barker, & Gfroerer, 2010). Respondents were asked how much difficulty they had doing each of eight activities "during the one month in the past 12 months when your emotions, nerves, or mental health interfered most with your daily activities." The eight items were assessed

on a 0 to 3 scale with categories of "no difficulty" (0), "mild difficulty" (1), "moderate difficulty" (2), and "severe difficulty" (3).

The SDS consists of a series of questions that is used to measure impairment in a person's daily functioning in four role domains. Respondents were asked how much their "emotions, nerves or mental health" interfered with each role domain "…during the month in the past 12 months when you were at your worst emotionally." The SDS role domains are assessed on a 0 to 10 visual analog scale with impairment categories of "none" (0), "mild" (1–3), "moderate" (4–6), "severe" (7–9), and "very severe" (10).

The K6 scale used to measure past-year nonspecific psychological distress consists of six questions asking frequency of symptoms during the month in the past year when the respondent was at his/her worst emotionally. Response options are "none of the time" (0), "a little of the time" (1), "some of the time" (2), "most of the time" (3), and "all of the time" (4). The sum of the values for the six questions is the K6 score (range 0–24).

The clinical diagnostic interview used in the MHSS is the Structured Clinical Interview for DSM-IV-TR Axis I Disorders Non-Patient Edition (SCID-I/NP). The SCID-I/NP (First, Spitzer, Gibbon, & Williams, 2002) is a semi-structured diagnostic interview that has been widely used in clinical components of studies such as the NCS-R (Kessler et al., 2004), the National Survey of American Life (Jackson et al., 2004), and the NSDUH substance-use disorders reappraisal study (Jordan, Karg, Batts, Epstein, &Wiesen, 2008). The interview was modified to assess past 12-month mental health disorders and functioning via telephone.

Diagnostic modules contained in the MHSS version of the SCID include mood disorders, psychotic disorders, anxiety disorders, eating disorders, impulse control disorders, substance use disorders, and adjustment disorders. Also included in the MHSS SCID is the DSM-IV Axis V GAF Scale, a clinical interviewer (CI) rating of the respondent's period of worst psychological, social, and occupational functioning during the past year. Functioning is rated on a scale from 1–100.

Field Interviewer (FI) and Clinical Interviewer (CI) Training

For the MHSS, all NSDUH FIs were required to review a MHSS handbook, complete a MHSS electronic training course, and attend a one-hour classroom training session (Colpe et al., 2010). Clinical interviews were conducted by master's and doctoral level mental health professionals who had been carefully and extensively trained to administer the SCID over the telephone. Training was led by four clinical supervisors (CSs)—experts in the DSM and the SCID—and was overseen by the lead author of the SCID. The study protocol included comprehensive instructions for identifying and managing distressed respondents as well as ongoing supervision and inter-rater training exercises for the clinical interviewers.

Protocol for Selection of SCID Subsample

At the end of the main NSDUH interview, a subsample of adult respondents was asked if they would be willing to participate in an additional study that would gather more information about their recent mental health history. The request was scripted as part of the CAPI interview, and field interviewers (FIs) did not know in advance which respondents would be selected. Selected respondents were presented with a Special Study Description for informed consent. Those agreeing to participate were given a $30 cash incentive in addition to the $30 they received for completing the main NSDUH. FIs collected contact information (first name, telephone number(s), and best days and times to call). Within two to four weeks of the NSDUH main interview clinical interviewers called respondents and conducted the SCID interview. CIs completed the SCID on paper and audio-recorded the interview (with permission).

Sample Design & Response Rates for the 2008 MHSS

The two primary objectives for the first year of the MHSS were to (1) determine which of the two impairment scales, used in combination with the K6 scale, provided the more accurate prediction of SMI in NSDUH and would therefore be administered to the entire sample of adults in the 2009 and later surveys, and (2) develop prediction models that will accurately classify NSDUH respondents as meeting or not meeting criteria for SMI. Half of the NSDUH adult sample was randomly assigned the WHODAS and the other half the SDS. A subsample of approximately 1,500 adult NSDUH participants was selected for the follow-up clinical interview (750 from each of the main study half samples). The SCID subsample was stratified, based on respondents' K6 scores, to optimize the sample allocation for prediction modeling. Strata were constructed according to seven K6 scoring bands. Sampling rates were substantially lower for K6 scores 0 to 7 under the assumption that clinical positives would be rare in that scoring range. Of the 2,291 NSDUH respondents selected for the follow-up interview, 1,977 agreed to participate (86%). Clinical interviews were completed for 1,506 of those (76%). The most common reason for noncompletion among those initially agreeing to participate was inability to contact respondents by telephone after repeated attempts (15%).

IV. MODEL DEVELOPMENT & ESTIMATION

A series of weighted logistic regression prediction models were developed in which the K6 and either the WHODAS or SDS (collected within the main study) were used as explanatory variables of SMI status (collected from the SCID interview; Aldworth et al., 2010). The response variable, Y, was defined such that $Y = 1$ when an SMI diagnosis is positive; otherwise, $Y = 0$. If X is a vector of explanatory variables, then the response probability $(\pi = \Pr(Y = 1 \mid X)$ can be estimated using separate weighted logistic regression models for each of the WHODAS and SDS half samples. For each model, a cut point probability π_0 was determined, so that if $\hat{\pi} \geq \pi_0$ for a particular respondent, then he or she was *predicted* to be SMI positive; otherwise, he or she was predicted to be SMI negative. Receiver Operating Characteristic (ROC) analyses were used to determine the cut point that resulted in (approximately) equal weighted numbers of false-positives and false-negatives, to provide nearly unbiased estimates. Models were evaluated based on three criteria: (1) model robustness (e.g., preference given to parsimonious models that could be implemented in other surveys collecting similar covariates), (2) minimization of misclassification errors in SMI prediction (i.e., exhibiting reasonable ROC statistics), and (3) reasonable SMI estimates based on the full 12-month data set (i.e., balanced across several demographic subgroups and across the WHODAS and the SDS half samples).

Model fit statistics and sensitivity analyses indicated that in combination with the K6, the WHODAS was a better predictor of SMI than the SDS. Consequently, this impairment scale was chosen for administration in the 2009 and subsequent surveys.

The final WHODAS prediction model for estimating SMI was determined as follows, with a cut point π_0 of 0.26972:

$$\text{logit}(\hat{\pi}) \equiv \log[\hat{\pi}/(1-\hat{\pi})] = -4.7500 + 0.2098X_k + 0.3839X_w \quad (1)$$

Where $\hat{\pi}$ refers to an estimate of the SMI response probability π for the model,

X_k refers to the recoded past year K6 score, where scores less than 8 were recoded as 0, and scores of 8 to 24 were recoded as 1 to 17, and

X_w refers to the sum of recoded WHODAS item scores, where item scores of 0 or 1 were recoded as 0, and item scores of 2 or 3 were recoded as 1.

SAMHSA also was interested in deriving model-based estimates of "any mental illness" (AMI). AMI, defined similarly to SMI with respect to the presence of a diagnosable mental disorder, does not require functional impairment from the disorder. After assessing a variety of models, the original SMI model was chosen to estimate AMI, using a cut point of 0.024. National model-based estimates for 2008 were 4.4% for SMI and 19.5% for AMI (SAMHSA, 2010). These prevalence rates, as well as patterns across subgroups and correlations with key variables (e.g., treatment), were compared with corresponding estimates from other studies and found to be similar.

V. KEY ISSUES & FUTURE DIRECTIONS

Updating the Models & Measuring Changes across Time

The MHSS has been continued with 500 clinical interviews completed in 2009 and 2010, and 1,500 planned for collection in 2011 and 2012, supported by funding from NIMH. However, a plan for incorporating the 2009 and subsequent SCID data into the production of SMI and AMI estimates has not been finalized. One approach would be to identify a new "best" prediction model each year using the additional clinical interview data. However, given the small size of the SCID subsample, the updated model would likely introduce substantial variability that would make trend analysis difficult. Data from the 2009 SCID sample produced parameter estimates similar to those from 2008, providing evidence that the 2008 models are reasonable. Therefore, the 2008 WHODAS model, parameter estimates, and cut points were used by SAMHSA to produce 2009 national estimates of SMI and AMI prevalence (4.8% and 19.9%, respectively). SAMHSA plans to continue to apply the 2008 model for 2010 estimation, but to re-evaluate after more SCID data are accumulated in 2011 and 2012.

Estimation of the Variance of SMI & AMI

Currently, the variance that has been estimated for SMI and AMI assumes that the prediction model is correct and the estimated parameters from the prediction model are the "true" parameters. That is, the calculation of the standard errors does not take into account the variability incurred by using a small sample based model to calculate predicted values which are then used to produce estimates of SMI and AMI. A study is currently underway to investigate methods for estimating the "true" variance.

Determining an Optimal Sample Design for Model-Based & Direct Estimates

Since one of the initial goals of the MHSS was to develop models for estimating SMI, the sample design oversampled cases with higher K6 scores and had very low sampling rates for cases with K6 scores below 4. In addition, the main NSDUH sampling rates varied by age and state. The resulting extreme variation in sampling weights created difficulties in the analysis, particularly due to the small number of cases with very large weights (primarily older adults with low K6 scores) that were diagnosed with SMI in the SCID. In addition, the shift in focus to include the estimation of AMI created a need for a more balanced design, so SAMHSA made adjustments to the sampling rates to attempt to address this, increasing the sampling rates for low K6 scores (beginning July 2009) and reducing the sampling rate for 18–25 year olds (beginning January 2010). However, a clear approach to make decisions about the design of the SCID subsample has yet to be determined.

Nonresponse Bias

Since the recruitment for the MHSS occurs after the main NSDUH interview is completed, there is a depth of information available for both the respondents and nonrespondents to the MHSS. This allows for the evaluation of nonresponse bias between the NSDUH interview and the clinical interview. Differences between MHSS respondents and nonrespondents on demographic variables as well as substance use, health status, and mental health status are being investigated. Preliminary results showed that adults sampled who initially refused to participate had much lower rates of mental health problems than NSDUH respondents, while those not completing the SCID interview after agreeing to participate (and collecting the $30 incentive) had rates similar to NSDUH respondents. Analyses will evaluate whether there is a relationship between the main study key outcome variables and propensity to respond, whether persons with low response propensities are similar to nonrespondents on key outcome measures, and whether there is a relationship between response propensity and the clinical mental health measures collected through the SCID. Results from these analyses will be used to assess the nonresponse bias and to better inform the adjustment for nonresponse via weighting.

Bias Corrected Alternative Estimators of SMI & AMI

The prediction model yielded estimates that are unbiased for the overall adult population because the chosen cut-point equalized the weighted numbers of false-positive and false-negative counts of SMI. However, the false-positive and false-negative counts may not necessarily be equally distributed within population subgroups. Within some domains, therefore, the models may yield biased estimates of mental illness. Studies are underway that investigate alternative estimates of mental illness that correct for this bias within domains.

Disorder Specific Estimates Using Data from the SCID

Although the primary goals of the MHSS study were to produce model-based estimates of SMI and AMI, the nationally representative SCID data potentially could be used to produce direct estimates of specific mental disorders. Direct disorder-specific estimates have been generated for each year of data collection, for 2008, 2009, and 2010, and by combining 2008–2010 data. Preliminary results indicate that disorder-specific estimates produced separately for each year of collection were unstable and affected by extreme weights, leading to a decision to not publish estimates at this time, but investigations are continuing.

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Planned Missing Data Designs in Health Surveys

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When designing a survey, researchers often must decide whether to abandon standard measures for shorter measures. Many survey methods are designed for relatively short data collection instruments (Groves et al., 2004). Telephone, Web, or mail surveys all require strict limits on the amount of information to be gathered to insure high response rates, reduce respondent burden, and increase the validity of the responses obtained. Long survey instruments can lead to increased respondent burden and satisficing—the tendency to answer with little cognitive effort, which decreases response validity (Krosnick, 1991). Researchers usually have two choices for keeping the survey instrument at a reasonable length: (1) decrease the number of concepts measured, which may decrease the utility of the data gathered, including the validity of the findings, and (2) measure multi-item scales with shortened scales or single items. For example, instead of using a full standard 30-item scale, a researcher may select only ten items to ask. This strategy may reduce reliability and, perhaps more importantly, hinder comparisons with published studies that use the full scales.

Planned missing designs (also referred to as matrix sampling) present a third option for health researchers. The length of a questionnaire can be reduced by decreasing the number of scale items asked of each participant, while the information still can be analyzed as if the full standard scale measures were used. This method retains full reliability and comparability to studies using complete measures. The cost is in statistical power; research goals requiring full statistical power should be assessed by measures and items collected from all study participants. Other research objectives can be addressed with lower statistical power for certain items or scales less central to the principal aims of the study. Scales or items in the questionnaire that do not require the statistical power of the full sample could benefit from a planned missing data design.

In a planned missing (PM) data design, entire sections of an instrument may be omitted for certain respondents, or respondents may receive only a partial version of a given section (Belin, Datt, Desmond, & Ganz, 1999). Items or scales to be included are randomly assigned to each respondent. A common PM design is the three-form design (Graham, Taylor, Olchowski, & Cumsille, 2006); it includes a set of items asked of everyone plus three randomly assigned sets of items, one set of which is included on each form, such that respondents receive two-thirds of the total survey items. Many other designs are conceivable, such as including a smaller percentage of the items asked or using more forms (Schafer & Graham, 2002). With multiple-item scales, either the whole scale can be dropped from a random sample of the surveys, or each respondent can be given a random subsample of the scale items (Graham et al., 2006). The main requirement is that for every pair of items in the survey, there should be a subset of respondents who answer both items. The relative sample size of these pairs affects the standard errors obtained when the data are analyzed (Bunting, Adamson, & Mulhall, 2002). Loss of statistical power is a concern, though it is often substantially smaller than researchers expect if efficient imputation methods are used (Enders, 2010). When items with PM data are correlated with other items included in the survey, the power lost can be quite small. In a simulation study with inter-item correlations of 0.3 and a three-form design leaving 33% of data missing, Enders (2010) found power for the covariances with the smallest proportion of cases to be within 90% of the power without a PM design. When the inter-item correlations were .1, however, the power for these was reduced to only 20% of that found when the PM design was not used. Because scale items tend to be substantially correlated with other items in the scale, a PM design to reduce the scale length is expected to have little impact on statistical power.

Accounting for all the observed data with a PM design requires that the analyst use modern techniques for the treatment of missing data. The most widely used techniques are multiple imputation (MI) and full information maximum likelihood (FIML) methods. MI replaces missing values with sets of plausible ones, accounting for the uncertainty arising from missing values by running the analysis on multiple data sets with complete information for all variables (Little & Rubin, 2002). Maximum likelihood techniques, commonly found in structural equation software (e.g., Mplus, Amos), allow for the estimation of multivariate models with incomplete data matrices. Recent developments in these techniques and user-friendly, accessible software have increased the practical utility of PM designs and the range of analysis models that can be applied (Johnson & Young, 2011).

In this paper, we describe the application of a three-form planned missing design to three health-related scales in the National Survey of Fertility Barriers (NSFB). The NSFB is a nationally representative probability sample of 4,700 women, ages 25–44, interviewed by telephone (Johnson & White, 2009). The study was designed to assess social and health factors that relate to the reproductive choices and infertility of American women. The theoretical model that guided this study built on medical health service utilization and help-seeking models. Multiple outcome, structural, and intervening variables were needed to test facets of the model. These included factors that contributed to help-seeking for infertility and social psychological, social structural, and economic outcomes for women and their partners. Due to budget reductions, a desire to limit respondent burden, and limitations of the survey mode, it was necessary to restrict the interview to an average length of 30–35 minutes. This required reducing the number of items in 21 multi-item scales measuring key concepts. We sought the shortest standard measures with acceptable reliability and validity then further reduced the number of items in some scales based on a pilot study conducted with 580 women living in Midwestern states. These steps helped reduce the length of the survey, but further reduction was necessary. We decided that a PM approach would reduce the survey length but still permit us to assess all the measures needed to meet study objectives.

We focus on only three of the health-related scales that all respondents were eligible to answer: (1) a ten-item version of the CES-D depression scale (Andresen, Malmgren, Carter, & Patrick, 1994), (2) a Medical Locus of Control Scale (Wallston, Wallston, & Devellis, 1978), and (3) an eight-item scale constructed for this study that assessed respondents' attitudes about the ethics of infertility treatments (Ethics of ART). The PM design and the wording of the items from the three scales used can be found in Appendix A. For the 21 scales included in the survey, including the three we focus on here, the scale items were divided into three sets. For each scale, one in five respondents was randomly selected to receive all items. Otherwise, each respondent received two of the three sets, the third set having been omitted at random. Because selection into the PM design occurred for each scale and for each respondent, all respondents were likely to have a shortened version of at least one of the scales. Overall, there were 96 items in the 21 scales subject to the PM design. For respondents who were eligible for all scales, the average number of excluded survey items was 38; this resulted in a savings of approximately five minutes in survey length. Respondents who neither had infertility problems nor sought treatment for infertility saved less time.

The three-form PM design we implemented differs from the designs described in the literature (Enders, 2010; Graham et al., 2006). With a conventional design, the entire instrument, rather than specific scales, is divided into parts—three subject to being dropped in the PM design and a fourth asked of every respondent. This is a practical strategy for paper-and-pencil questionnaires because only four versions must be designed and printed. A computer-assisted telephone interviewing (CATI) system offers researchers greater design flexibility because there can be as many versions of the questionnaire as there are respondents. In the NSFB design, each scale was divided into three parts, each containing approximately

two-thirds of the scale items, and separate random numbers were used to assign each scale to each respondent. This strategy had the advantage of increasing the randomness of the distribution of PM items and reducing problems estimating higher-order interaction effects among variables appearing in different forms (Graham et al., 2006). In our design, no restrictions are imposed on the levels of interaction effects between scales that can be estimated.

Rather than dropping items within scales, an alternative strategy, also designed for the flexibility of a CATI system, is the random dropping of entire scales. This approach simplifies the process of imputing the PM data and incorporating whole scales into analyses with FIML methods. Imputation is simplified because the imputation model can be set to impute summated scale scores rather than the actual items, which greatly reduces the number of variables in the imputation model. Maximum likelihood approaches require the estimation model to include equations that combine items for the linear creation of scale scores. For scales with many items, computation time would increase substantially, as well as the odds of failed estimation. Dropping whole scales, however, has been found to yield lower power then dropping a fraction of scale items (Graham et al., 2006). We choose the item-level approach because of plans to use some single items from the scales in analyses and because some of the investigators on the project had concerns about deleting whole scales for some respondents. The large number of variables in the dataset that needed to be imputed complicated, but did not prevent, the imputation of a dataset which accounted for all PM values.

The specific PM design we used appeared to be unique; no other surveys using a similar design could be found. We added components to our design to aid in evaluating the quality of the data obtained and to assess whether our design would affect the substantive results. Beginning about one-third of the way into the data collection process, we decided to modify the basic PM design by randomly selecting one of five respondents to receive all items in a scale. This allows us to compare characteristics and reliability of the scales that did and did not include a PM component. To reduce potential selection bias, we restrict our analysis here to respondents interviewed after the design change occurred. This reduced our sample size to approximately 2,700 respondents.

IMPUTING WITH A PM DESIGN

The missing data that occurs with a PM design has been randomly assigned, and is therefore missing completely at random (MCAR). When data are MCAR, the statistical characteristics (mean, distribution, etc.) of the variable are unbiased estimates of the values that would have occurred had all cases been observed. This pattern of missingness allows for use of imputation and maximum likelihood methods to maximize use of the data that were observed. Compared to maximum likelihood approaches, imputing PM values is advantageous as a general data analysis strategy because it generates a complete data matrix, though both strategies yield nearly indistinguishable results in multivariate models (Johnson & Young, 2011). For the NSFB data, an imputed version of the PM design items was included in the public release data set. We evaluate imputation strategies in this paper.

A number of imputation approaches have been developed and described elsewhere (Johnson & Young, 2011; Schafer & Graham, 2002). One widely implemented approach has been the normal multiple imputation model, implemented in several forms in SAS, Stata, SPSS, R, and others. When the missing data are MCAR or missing at random (MAR), this approach yields proper unbiased estimates that take into account the uncertainty introduced by the missing values. Multiple data sets (five or more) are generated that vary only in the values assigned to the missing data. Statistical analysis is conducted separately in each

data set, and the separate estimates are combined using Rubin's Rules so that the standard errors reflect the uncertainty of each imputed value.

The normal model requires the assumption that all variables are quantitative and continuous, with a multivariate normal distribution. As a result, the imputed values follow a normal continuous probability distribution. Although measures rarely conform to this assumption, simulation studies have shown that the method is quite robust to violations. The imputed values in the normal model are also likely to assume decimal values and values beyond the range of the observed data. For example, a variable with four ordinal categories (1, 2, 3, 4) may be imputed with a decimal (e.g., 2.87) or outside the range (e.g., 4.92). For applications involving multivariate models that rely on variables' covariance (e.g., regression and structural equation models), the univariate distribution of the imputed values is of little concern, and, therefore, it is entirely appropriate (and recommended) to leave imputed values "as is."

For other uses, particularly when a large fraction of the data are imputed, discrepancies between the distribution of observed values and missing values may be problematic, as imputed values will follow a normal distribution even when the observed distribution is quite different. Some scales may have established cutoff scores that indicate pathology, for example, but these cutoff points may be biased if the distributions of the imputed data vary widely from the distribution of the observed data. Here we evaluate three strategies that can be used to solve this problem. The first is to use an imputation approach that treats the response categories as nominal and uses multinomial regression to generate the imputed values. This "tailored" approach does not require the fully normal assumption for the imputed variables and usually leads to distributions that more closely approximate the observed distribution. The second approach we use here is to calibrate the imputed values to match the observed distribution. Yucel, He, and Zaslavsky (2008) developed a procedure for calibrating the values under a MCAR model. We have implemented this approach in a Stata ado, available by request from the authors. A third common strategy is to round the values to fit within the observed range. This "naïve" rounding strategy modifies the imputed values to parallel the observed values but does not yield matching distributions and may create biased estimates (Horton, Lipsitz, & Parzen, 2003). While this strategy is not advisable, we include it here because it is commonly employed with implausible values.

A final strategy for handling missing values in scales is to use information only from the available items. For example, if observed values are available for six of the ten items in the scale, the mean of the six items can be computed and used for that respondent. If a summated score for the scale is used, the mean can then be multiplied by the total number of items in the scale to yield the same range. Schafer and Graham (2002) describe this approach and conclude that, although it is not optimal, it is likely to yield reasonably unbiased estimates, particularly if the missing pattern is MCAR.

These data were imputed using the ICE program in Stata. The imputation models were informed by all items in the three scales used here and an additional set of three variables in the data set, which were used to improve predictions of the unknown values. We generated 25 imputed data sets. One set of imputed values employed the normal model and assumed all variables were quantitative and continuous. Next, these values were modified in two ways: (1) the imputed values were calibrated using the Yucel, He, and Zaslavsky (2008) method and (2) the values were rounded and recoded to fit the observed range. The tailored model also was generated with ICE, using a multinomial logistic regression as opposed to linear regression, for the predictive equations for the imputed values. The scales were created as summated scores after the item-level data were imputed; we created an available-item scale score from the mean of available (nonmissing) items, multiplied by the total number of scale items. We also present results from a subsample

of respondents who were asked to respond to the full scale. For the purposes of this study, we did not use the sample weights.

FINDINGS

We begin by examining descriptive information on each version of the three scales. Table 1 presents the averaged means and standard deviation of each version from each of the 25 imputed data sets. Each strategy produced very similar results. For the CES-D scale, the mean score rounded to two digits was 17 for all, but varied slightly with more digits of accuracy. The respondents who received all items had the lowest mean and the available-item strategy produced the highest standard deviation. Mean and standard deviations of the various versions of the other two scales were also very similar.

Table 1 also presents the Cronbach's alpha reliability coefficient for each version of the scales, except the available-items scale, for which alpha cannot be calculated. These were remarkably similar to each other and to the reliability for respondents receiving all items. The planned missing design did not result in a loss of scale reliability. The CES-D was the only scale where alpha was slightly higher for those not in the PM design. We conclude that a PM design with imputed data can yield scale reliability estimates approximately the same as would be found if no PM design were used.

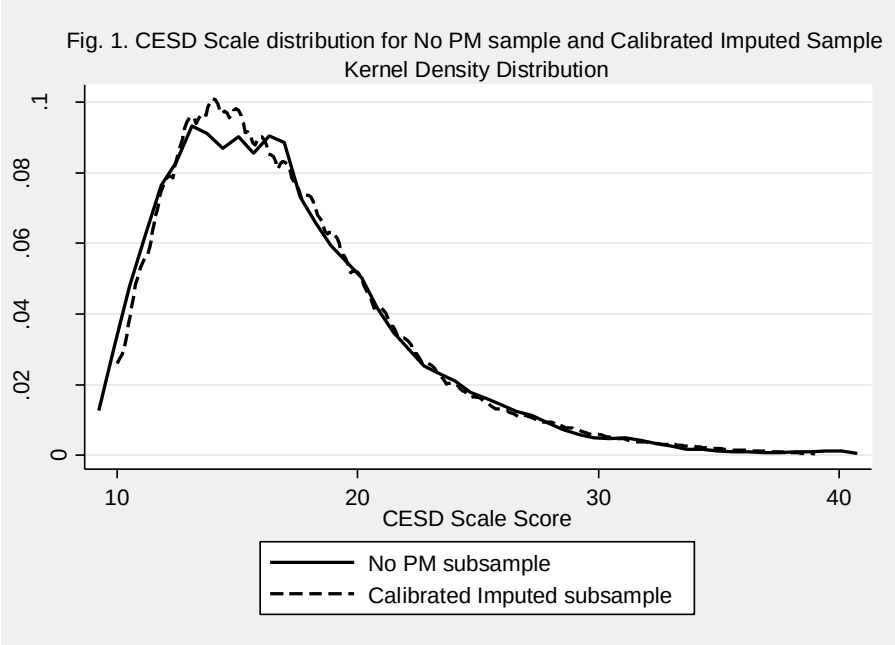
Table 2 presents the correlations among the different estimates for the respondents in the PM design. For all three scales, the mean of the available items had the lowest average correlations with the imputed estimates. All correlations were over 0.9, many in the 0.99 range. We conclude that the approaches yield similar estimates as indicated by the high correlations among them.

Table 1. Descriptive Information & Alpha Reliability of the Scales

	CES-D (10 items)			Medical Locus of Control (6 items)			Ethics of ART Scale (8 items)		
CODING OF PM RESPONSES	Mean	SD	Alpha Mean	Mean	SD	Alpha Mean	Mean	SD	Alpha Mean
Respondent received all items (no PM)	16.67	4.94	0.82	17.44	2.34	0.74	13.04	3.77	0.84
Available items scale	17.02	5.05	—	17.63	2.91	—	12.95	3.82	—
Imputed with normal model	17.00	4.84	0.80	17.61	2.67	0.78	12.97	3.70	0.85
Calibrated imputed normal model	16.96	4.78	0.79	17.61	2.60	0.76	12.97	3.64	0.84
Imputed with tailored (multinomial) model	17.02	4.86	0.80	17.59	2.68	0.78	12.99	3.69	0.85
Naïve rounding of normal model	17.20	4.68	0.79	17.59	2.66	0.77	13.03	3.62	0.85

Table 2. Correlations among Five Strategies for Handling PM Values for the Three Scales

PM METHOD USED	CESD Mean of Available Items (M)	CES-D (M)	CES-D (N)	CES-D (T)	CES-D (C)
	CESD Normal (N)	0.971			
	CESD Tailored (T)	0.970	0.950		
	CESD Calibrated (C)	0.971	0.992	0.951	
	CESD Rounded normal (R)	0.974	0.994	0.953	0.994
	Ethics Mean of Available Items (M)	**Ethics (M)**	**Ethics (N)**	**Ethics (T)**	**Ethics (C)**
	Ethics Normal (N)	0.930			
	Ethics Tailored (T)	0.934	0.943		
	Ethics Calibrated (C)	0.934	0.986	0.944	
	Ethics Rounded Normal (R)	0.936	0.987	0.946	0.995
	Medical Locus Mean of Available Items (M)	**MLOC (M)**	**MLOC (N)**	**MLOC (T)**	**MLOC (C)**
	Medical Locus Normal (N)	0.931			
	Medical Locus Tailored (T)	0.929	0.914		
	Medical Locus Calibrated (C)	0.921	0.986	0.910	
	Medical Locus Rounded Normal (R)	0.926	0.988	0.908	0.9904



Similarities in the means, standard deviations, and high correlations may still result in different distributions, which may have substantive consequences when using the PM approach. In the next step, we compared the distributions resulting from the different approaches. Because the calibrated approach is likely to reflect the distribution at the item level most accurately, we compare the distributions of the calibrated imputed sample with the distributions of the scales in the subsample of respondents who were given all items. Figure 1 compares the distributions for the CES-D, using a kernel density estimator. As can be seen, the distributions are very similar. For this scale which has used cutoffs for determination of depression pathology, we also compared the cumulative frequency distributions to determine the proportion of cases below cutoffs of 20 and 30. The percentage of values above the cutoff in both cases ranged from the same to within 0.1%. Distributions were also similar for the Ethics of ART scale.

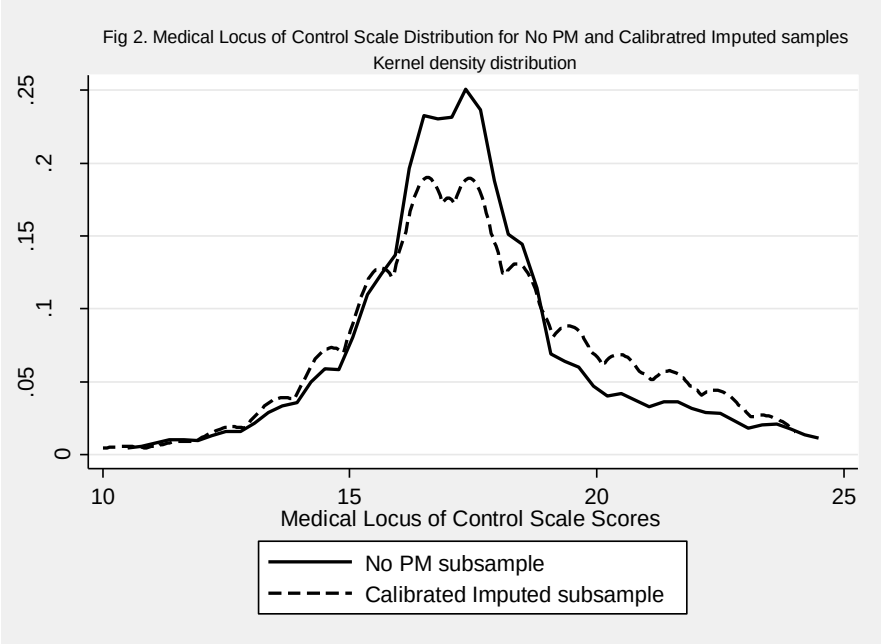


Figure 2 compares the distributions for the calibrated version of the imputation to the all-item version of the Medical Locus of Control Scale. While very similar, the difference in distributions is larger than was observed for the CES-D scale. The distribution in the no-PM subsample was more peaked, with a greater proportion of the cases falling near the mean and fatter tails for the calibrated measure. We explore possible reasons for this difference in a later table.

In Table 3 we explore whether there were differences in the scales depending on the specific set of items that were excluded in the PM design. In this model we use regression analysis to examine differences in the scores depending on the set of items received by the respondent. The PM set used was coded into dummy variables, with the omitted (reference) group consisting of the set in which respondents received all items. For the CES-D scale, only one set (set 1) was significantly different from the respondents receiving all items, and only for the available-items version. For all other versions, there was no significant difference between the PM sets and the non-PM group. For the Ethics scale, two sets differed significantly with the available item measure, but only set 2 differed significantly for all but the rounded version. Set 2 yielded significantly lower mean scores for the scale. This might reflect the exclusion of items on egg donation and in vitro fertilization (IVF). For the Medical Locus of Control Scale, all three sets differed significantly from the scores of those receiving all items on the available-items measure, but only set 2 differed significantly from this group for the other four measures. When the scale was asked without items 3 and 4 ("When I get sick, I am to blame" and "If I take care of myself, I can avoid illness") higher scores were obtained in all versions. When the responses to the individual items in the scale were examined, the only items with significantly higher scores for set 2 were the last two items on the scale. Apparently, omitting items 3 and 4 affected how items 5 and 6 were answered—perhaps evidence for an effect of item ordering on responses. These results raise cautions that omitting items may alter the responses to the remaining items in the scale.

Table 3. Regression Models of Scales on PM Set Asked of Respondent[†]

SCALE	Available Items *b*	Normal Model *b*	Calibrated Normal *b*	Tailored Model *b*	Rounded Normal *b*
CESD Scale					
Set 1	0.672*	0.227	0.088	0.228	0.438
Set 2	–0.037	0.247	0.202	0.278	0.449
Set 3	–0.292	–0.303	–0.250	–0.274	–0.113
Constant	16.937	16.941	16.940	16.944	16.942
Ethics of ART Scale					
Set 1	0.436*	0.039	0.031	0.031	0.108
Set 2	–0.393	–0.473*	–0.414*	–0.472*	–0.371
Set 3	–0.412*	0.163	0.105	0.170	0.216
Constant	13.045	13.028	13.032	13.028	13.035
Medical locus of Control Scale					
Set 1	–0.379*	0.009	0.091	–0.008	–0.026
Set 2	1.378**	0.442**	0.307*	0.414**	0.437**
Set 3	–0.370*	0.169	0.211	0.126	0.145
Constant	17.446	17.442	17.443	17.442	17.442

[†] Respondents asked all scale items are the comparison group.
*$p < .05$, **$p < .01$.

The final table selects two variables in the data set, a Life Satisfaction Scale and Self-Reported Health, and explores differences using a regression model in the effects of the three scales on these outcomes in equations, including a number of background and control variables. We only present results for the available-item, normal imputed, and calibrated normal models. Results from the other models (by request) are similar to the results reported here. The three ways of handling the PM data had little effect on results

for both outcome variables. The largest differences in the *b*-coefficients is found for the effect of the Medical Locus of Control Scale on Life Satisfaction, where the effect was substantially smaller for the normal imputed version than for the calibrated and available-item mean versions.

Table 4. Regression Models for Effects of Three Ways of Coding PM Data on Life Satisfaction & Self-Reported Health

	Life Satisfaction Scale†			Self-Reported Health (1 = Poor, 4 = Excellent)‡		
INDEPENDENT VARIABLES	**Mean of Available Items *b***	**Normal Imputation *b***	**Calibrated Normal Imputation *b***	**Mean of Available Items *b***	**Normal Imputation *b***	**Calibrated Normal Imputation *b***
CESD Scale	–0.109***	–0.114***	–0.114***	–0.025***	–0.026***	–0.027***
Ethics of ART Scale	–0.082	-0.012	–0.020	–0.068	–0.007	–0.008
Medical Locus of Control Scale	0.176***	0.118***	0.189***	0.016**	0.017**	0.017**
Constant	11.170***	14.170***	11.080***	3.566***	3.562***	3.589***
N	2,658	2,708	2,708	2,658	2,708	2,708
Adjusted R^2	0.321	0.315	0.314	0.276	0.269	0.277

†Controlling for religiosity, economic hardship, biomedical barriers to conception, presence of a chronic illness, self-report of health, presence of mental illness, self-admission of infertility, age, education, marital status, race, and religion.
‡ This controls for all variables in the first model except self-reported health.
*p < .05, ** p < .01, ***p < .001.

DISCUSSION & CONCLUSIONS

Our findings suggest that a planned missing approach is a viable option for assessing health-related scales when there are concerns about respondent burden and interview length. Our analysis demonstrated that when proper tools and methods are used to impute the values for variables excluded by the PM design, the measures yield reliable scales with means and distributions closely matched to what would be found if all the items had been queried. Although imputing the PM data can be an onerous and time-consuming task increasing the analyst burden, particularly if there is a desire to impute all PM data in a large survey, new imputation and calibration tools are available that can facilitate this process. If the researcher chose to leave the PM missing values in the data set and only deal with missing data in the analysis of specific research problems, then the presence of these missing cases would be less of a chore. In this circumstance, it is likely that the researcher would need to impute missing data for other variables also, and the imputation of the planned missing values would be carried out as part of that process.

The most serious concern we encountered that suggests some caution in using a PM design such as used here was the evidence that omitting items in the middle of a scale may affect responses to items asked later. It would be possible to avoid this ordering effect in two ways. First, items can be randomly rotated to reduce an order effect. Second, a PM design can be used that randomly drops whole scales for some of the survey respondents. The advantage of this second approach is that everyone assessed on the scale gets the same set of items. The disadvantage is some reduction in statistical power.

Many possible types of PM designs can be tailored to the specific needs of the research. These need not follow the basic three-form design or the design used here. The proportion of respondents dropped for specific questions can also be smaller or larger depending on the needs of the research. For example, in a large survey of health care utilization in 15 markets with over 10,000 respondents, there was an interest in assessing whether social desirability response tendencies may have affected reports of adherence to physicians' recommendations. Including a multiple-items social desirability scale on all surveys would increase respondent burden and distract from the main objective of the study. Including the scale on only a

random fraction of the respondents, perhaps even as little as 25–50%, and imputing values for the rest, would allow the social desirability scale to be included in multivariate models without decreasing the power of other variables but would still test for social desirability effects.

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Appendix. Items & Planned Missing Design for the Three Scales

Scale		Question Wording	Planned Missing Set 1	2	3
CES-D†	1	I was bothered by things that usually don't bother me.		x	x
	2	I had trouble keeping my mind on what I was doing.		x	x
	3	I felt depressed.		x	x
	4	I felt that everything I did was an effort.	x		x
	5	I felt hopeful about the future.	x		x
	6	I felt fearful.	x		x
	7	My sleep was restless.	x	x	x
	8	I was happy.	x	x	
	9	I felt lonely.	x	x	
	10	I could not get going.	x	x	
MLOC‡	1	If I get sick, it is my own behavior which determines how soon I get well again		x	x
	2	I am in control of my health		x	x
	3	When I get sick, I am to blame	x		x
	4	If I take care of myself, I can avoid illness.	x		x
	5	If I take the right actions, I can stay healthy.	x	x	
	6	The main thing which affects my health is what I myself do	x	x	
Ethics*	1	Helping a woman get pregnant by inseminating her with her husband or partner's sperm?		x	x
	2	Helping a woman get pregnant by inseminating her with sperm from a donor.		x	x
	3	Using In vitro fertilization, or IVF.	x		x
	4	Using the eggs of a donor.	x		x
	5	Using a surrogate mother.	x	x	
	6	Using a gestational carrier.	x	x	
	7	Some medical procedures used to help people have children increase the chance of twins, triplets, or more.	x		x
	8	When a large multiple pregnancy occurs, it is possible to remove some of the fetuses in order to reduce the risk to the remaining fetuses. For example, it is possible to reduce a quadruplet pregnancy to a twin pregnancy.	x	x	

† The response options were read in this order: (1) rarely or never, (2) some of the time, (3) quite a bit of the time, or (4) all the time. Items 5 and 8 were reverse coded. High scores indicate more depression.

‡ The response options were given as: Please indicate whether you (4) strongly agree, (3) agree, (2) disagree, or (1) strongly disagree. High scores indicate greater control.

* The response options were given as: Do you think this causes (1) no ethical problem, (2) some ethical problems, or (3) serious ethical problems? High scores indicate greater ethical problems.

Advancing the Measurement of Health Status and Health Behaviors through Modern Test Theory

Adam Carle (University of Cincinnati)

1. INTRODUCTION

Health surveys frequently rely on fallible self-report data, with participants reporting on themselves. Thus, they typically measure participants' health statuses and behaviors only indirectly. This leads to challenges. In this paper, I briefly review some of these challenges and discuss modern test theory and related measurement models as tools for addressing them. These models include item response theory (IRT), confirmatory factor analysis (CFA), and structural equation modeling (SEM)-based models (e.g., multiple group [MG] multiple cause multiple indicator [MIMIC]). Each uses mathematical models to describe how individuals respond to questions. Equations describe the relations among item responses, and equations' parameters provide empirical assessments of the questions' measurement properties. With them, one can make empirically based decisions about measurement quality.

2. CHALLENGES IN MEASURING HEALTH STATUSES AND BEHAVIORS

2.1 Reliability

When measuring constructs indirectly, random measurement error influences measurement (McDonald, 1999), leading to unreliable measurement. Reliability refers to the concept that, if respondents answered a set of questions under the same circumstances, they should give the same answers each time (McDonald, 1999). Despite best efforts, random measurement error will influence responses. Without reliability, it is unclear whether survey responses have captured the construct of interest. With high reliability, one feels confident that random measurement error does not influence responses. Respondents would consistently receive a similar value on the question(s) of interest. Low reliability suggests that respondents may give a response or receive a score based on random measurement error rather than their "true" status. Subsequently, any research or decisions would be based in error. To date, too little survey research has addressed reliability (Carle, Blumberg, Moore, & Mbwana, 2011).

When survey research has addressed reliability, it has tended to use the traditional classical test theory approach (Carle et al., 2011), which treats reliability as a constant. It does not allow for the possibility that some questions may provide more reliable measurement at higher (or lower) health status levels (Embretson & Reise, 2000). For example, consider a question that asks respondents to describe illegal behavior related to alcohol use. Respondents may dwell on the question due to its sensitive nature. This could lead to consistent, reliable responses. However, describing legal behavior may not cause as much concern. Thus, respondents may provide less consistency in these responses. If this occurs, the questions would provide excellent reliability for individuals engaging in illegal behavior (likely those with high problem levels), but poorer reliability for those with less severe problems. Researchers should acknowledge that reliability can differ across construct levels (Carle et al., 2011).

Parameters in measurement models explicitly address this possibility. In SEM-based models, loadings describe how strongly questions relate to the construct (Bollen, 1989). In IRT, the discrimination parameters provide similar information (Hambleton, 1985). High loadings or discrimination parameters indicate questions that provide reliable measurement. A second set of parameters in the models indicate at what

construct level responses prove most reliable. In IRT, location parameters give the level of the underlying construct at which respondents are more likely than not to endorse an item (Embretson & Reise, 2000). Thresholds provide similar information in SEM (Muthén, 1984). Responses to questions are most reliable at the threshold (in SEM) and discrimination (in IRT) values.

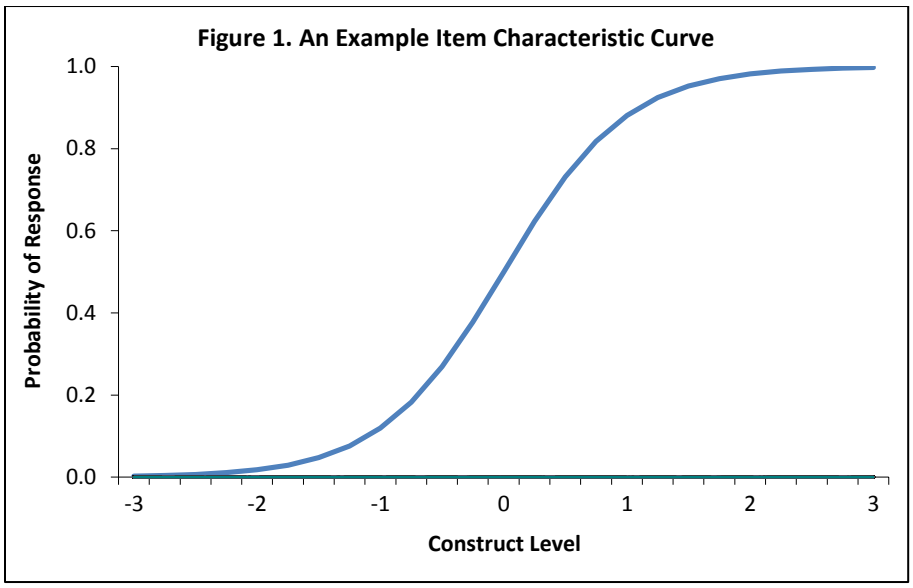


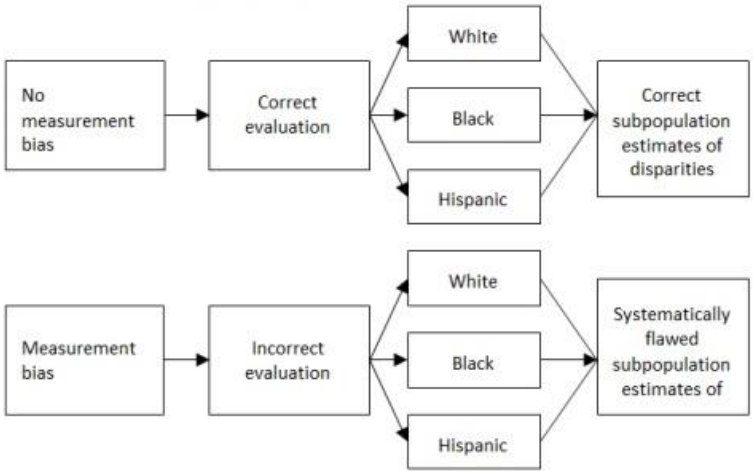
Figure 1 provides an example of an item characteristic curve (ICC). One can generate ICCs from both SEM- and IRT-based models. Values of the measured construct fall along the x-axis, while the y-axis reflects the probability of endorsing the question. The ICC depicts how the probability of endorsing the question changes as levels of the construct increase. At low levels, individuals will not likely endorse the question. At the location (threshold) parameter's value, the probability that an individual will endorse the question surpasses 50%. The slope of the curve reflects reliability. The steeper the curve, the more reliably the question discriminates between individuals at a given level of the measured construct (Embretson & Reise, 2000).

Using ICCs, a researcher can examine whether responses to a question tend to provide reliable measurement (e.g., is the ICC steep?) and at what levels responses provide their most reliable measurement (e.g., where is the ICC steepest?). If a researcher seeks to reliably measure a construct across all levels, one would want a set of questions with steep ICCs but with location/threshold parameters dispersed across levels of the construct. Alternatively, if seeking to measure only one level of a construct, one would want a set of questions with steep ICCs but with location/threshold parameters clustered around a specific construct level. In this way, health survey methods researchers can make empirically informed decisions about which questions to include on a survey questionnaire.

2.2 Internal Validity

As a second challenge, measurement in health surveys may lack internal validity. Health surveys often use a set of questions to measure a single construct (e.g., alcohol dependence) and subsequently create a summary score based upon the set. If the researcher expects that the questions measure a single construct, internal validity refers to the extent to which empirical data support the hypothesis that the questions measure a single construct (McDonald, 1999). Scoring systems should have internal validity in order for the scores to have meaning. Unfortunately, few studies have examined internal validity in health surveys.

Figure 2. An Example of Measurement Bias' Influence on Population Health Measurement



2.3 Measurement Bias

Health surveys also should have equivalent internal validity and psychometric properties across various subpopulations (e.g., Whites, Blacks, Hispanics). The possibility exists that participants respond to questions about themselves differently depending on their social and economic (SES) backgrounds or other characteristics. This possibility, a form of systematic measurement error often labeled measurement bias or differential item functioning (DIF), refers to the fact that two individuals with an identical underlying health status may nevertheless respond differently to questions asking about their health. For example, two people with equivalent alcohol dependence behavior levels may respond differently to questions about their alcohol use due to culturally divergent beliefs about discussing their alcohol use. One may feel free to discuss his/her behavior, while the other does not. Thus, despite equivalent pathology, the two would appear dissimilar based on their responses to questions. As a result, efforts to understand individuals' health based on their responses to questions about their health would include systematic flaws (see Figure 2).

Measurement bias leads to the possibility that observed health disparities may reflect measurement bias rather than true differences. This leaves unclear whether the results of health surveys across subpopulations reflect true differences or bias. Bias can obscure differences, decrease reliability and validity, and render group comparisons impossible (Carle, 2009a; 2009c). Without establishing equivalent measurement, the field cannot (1) draw strong conclusions about disparate outcomes, (2) support evidence-based practice and policy, or (3) address health disparities.

Modern test theory and related measurement models offer a powerful set of models capable of tackling the challenges identified above (Bollen, 1989; Carle, 2010; Hu & Bentler, 1998; Muthén, 1989). However, little work integrates these models into health survey research, impeding the advances they could bring. In addition to investigating bias, these methods can correct for bias, allowing more valid comparisons across groups. These models have seen few applications in health survey research methods. Thus, I briefly describe them here and provide an example of using them to evaluate a set of survey questions about alcohol dependence.

3. MEASUREMENT MODELS AS A SOLUTION

3.1 Multiple Group Multiple Indicator Multiple Cause Models

SEM-based Multiple Group Multiple Indicator Multiple Cause (MG-MIMIC) models offer a potent method to investigate the psychometric properties of health surveys, including whether one can form a single summary score based upon responses and whether responses to questions provide suitable reliability and internal validity, both generally and equivalently across subpopulations. MG-MIMIC models extend "traditional" models by incorporating additional background variables as covariates in SEM (Jones, 2003; 2006; Carle, 2010; Muthén, 1989). Rather than limiting analyses to a single variable as traditional approaches do, the MG-MIMIC approach simultaneously controls for differences in responses due to some variables (e.g., education and income) and allows an investigation of bias across another (e.g., race or ethnicity)(Carle, 2010; Jones, 2006). Moreover, MG-MIMIC models provide empirical measures of internal validity (Bollen, 1989). With them, one can directly examine the validity of creating a single summary score.

First, consider the model. Let Y_{ij} equal the i^{th} individual's score on the j^{th} ordered-categorical item (question), let the number of items equal p (j = 1, 2,...p), and let the number of item responses range (0, 1,…s). For simplicity, consider a dichotomous item (i.e., responses 0 or 1). The model assumes that a latent response variate, Y_{ij}^{*}, determines responses. The variate corresponds to the idea that, although observed responses fall into discrete categories (e.g., no/yes), an underlying continuum represents the possible responses. A threshold value on the variate determines responses. If an individual's value on the latent response variate is less than the threshold, the individual won't endorse the item (i.e., will say "no"), but, if their value is greater than the threshold, the individual will endorse the item. Formally:

$$Y_{ij} = m \text{ if } \tau_{jm} \leq Y_{ij}^{*} \leq \tau_{j(m+1)} \tag{1}$$

where τ_{j1} is the latent threshold parameters for the j^{th} dichotomous item. As noted above, one can use the thresholds to estimate the level of the construct at which individuals will likely endorse an item.

Further suppose that some factor(s), η, is responsible for responses Y_{ij}^{*} relates to the factor(s) as follows:

$$\mathrm{Y}_i^{*} = \upsilon + \Lambda_y \eta_i + \varepsilon_i \tag{2}$$

v_j is a latent intercept parameter, λ_{yj}' is an r x 1 vector of factor loadings for the j^{th} variable on r factors, η_i is the r x 1 vector of factor scores for the i^{th} person, and ε_{ij} is the j^{th} unique factor score for that person. The loadings, similar to correlations, represent the degree to which an item relates to the factor(s); the greater the value of the factor loading, the greater the relation between the item and the latent variable. As noted above, the loadings provide an indication of reliability. Intercept parameters give the expected value of an item when the value of the underlying factor(s) is zero. Uniquenesses include sources of variance not attributable to the factor(s). As a result, the uniquenesses also provide information about reliability. As a uniqueness value increases, the reliability of an item decreases (Bollen, 1989; Carle, 2010).

Through two equations, MG-MIMIC models expand Equation 2 to include background covariate(s) that can directly influence the latent variable's measurement and the latent variable itself. The first allows the covariate to directly influence the measurement of the latent trait:

$$\mathrm{Y}_i^{*} = \upsilon + \Lambda_y \eta_i + \Gamma_y \mathrm{x}_i + \varepsilon_i \tag{3}$$

The second, a structural equation, allows the covariate to predict the latent variable:

$$\eta_i = \alpha + \Gamma_\eta x_i + \zeta_i \quad (4)$$

α describes the latent trait's mean value, ζ indicates residuals in the structural model, and $\gamma_{\eta i}$ captures the covariate's influence on the latent variable.

To investigate bias, one subscripts measurement parameters to allow for group differences. Then, one constrains some or all of the measurement parameters to equality across groups and tests the constrained model's fit compared to a less constrained model. If fit indices indicate the constraints' acceptability, measurement equivalence exists. If not, bias presents. Once one has developed a final model, one can use model-based estimates to compare the health of various groups, removing the error that bias introduces.

In the remainder of the manuscript, using data from the National Epidemiologic Survey on Alcohol and Related Conditions (NESARC) (Grant, Kaplan, Shepard, & Moore, 2003), I describe a MG-MIMIC analysis. I show how measurement bias as a function of income, educational attainment, and minority status can lead to erroneous conclusions about alcohol dependence. I show how model-based estimates can mitigate this error (Carle, 2010).

3. METHODS

3.1 Participants

Participants (16,109 non-Hispanic White [hereafter White], 4,072 non-Hispanic Black/African-Americans [hereafter Black], and 4,819 Hispanic) were a subset of the 2001–2002 NESARC data designed and sponsored by the National Institute for Alcohol Abuse and Alcoholism. The original sample consisted of 43,093 noninstitutionalized U.S. adults age 18 and older. The complex multistage design oversampled Black, Hispanics, and adults age 18–24. Sample weights adjust the data to make it representative (Grant, Kaplan, et al., 2003). My analyses included White, Black, and Hispanic participants with complete data who reported on their alcohol consumption in the past 12 months.

3.2 Measures

Alcohol Dependence. Alcohol dependence is a maladaptive alcohol use pattern that leads to significant impairment or distress. It demonstrates at least three of seven criteria identified by the DSM-IV (American Psychiatric Association, 1994). The NESARC's Alcohol Use Disorder and Associated Disabilities Interview Schedule-IV (Grant, 1997; Grant, Dawson, & Hasin, 2001; Grant et al., 2003; Grant, Harford, Dawson, & Chou, 1995; Harford & Muthén, 2001; Hasin, Grant, & Cottler, 1997; Hasin & Paykin, 1999), uses 27 dichotomous items (0 = Yes, 1 = No) to operationalize these criteria. My analyses used all 27.

Ethnicity. Five options coded race. A single item allowed Hispanic self-identification. I considered individuals White if they identified as White and non-Hispanic, Black/African-American if they identified as Black/African-American and non-Hispanic, and Hispanic if they identified as Hispanic.

Income. Participants reported their total past 12 months' personal and family incomes. From this, the NESARC estimated household income (hereafter income). I used centered income, which allowed me to interpret bias attributable to this variable in terms of how differences from the average income level.

Educational attainment. I used centered years of education.

3.3 Analytical Approach

I examined measurement invariance following the method described by Millsap and Yun-Tein (2004), Carle (2010), and Woods (2009). I used fit index levels identified by the literature (Hu & Bentler, 1998; 1999; Steiger, 1998): After identifying bias using omnibus fit criteria, I used item level comparisons to identify the source of bias and modify the model accordingly. Constraints that led to significantly decreased fit identified bias. I subsequently freed these constraints to develop a partial invariance model. All analyses used Mplus, its theta parameterization and robust weighted least squares estimator, and appropriately incorporated the complex sampling design and weights in Mplus (Muthén & Muthén, 2009). I used zero-weighting (Korn & Graubard, 2003) to create the subsample (Carle, 2009b; Korn & Graubard, 2003).

4. RESULTS

4.1 Evaluating Internal Validity

I first examined whether the question set measured a single construct. This provided a test of whether data reflected the theoretical assumption that responses measured alcohol dependence only and whether alcohol dependence appears to be a single construct (Harford & Muthén, 2001l; Muthén, 1995). Thus, I tested a single factor alcohol dependence model (Model 1) across Whites, Blacks, and Hispanics. Model 1 allowed income and educational attainment each to have direct effects on each of the items (within statistical identification limits) and allowed income and educational attainment to correlate.

For statistical identification, Model 1 fixed the factor mean and variance at one and zero for Whites, while freely estimating the Black/African-American and Hispanic means and variances. Additional statistical identification constraints required constraining all groups' item intercepts to zero, fixing the direct effect of income and educational attainment on the "usual number of drinks had less effect" item to zero in all groups, constraining the loading for the "drinks" item to equality across the groups, constraining the threshold for the "drinks" item to equality across the groups, and fixing the uniquenesses to one for all groups. This method used the "anchoring" method described by Woods (2009). Model 1 included no other constraints. Model 1 fit the data well (RMSEA = 0.014; CFI = 0.98; TLI = 0.98; χ^2 = 2918.43, 1151; n = 25,000; p < 0.01). This provided evidence for internal validity within and across the groups.

4.2 Evaluating Measurement Bias

Given good fit, I tested Model 2, which constrained the direct effects of income and educational attainment to zero across all groups. These constraints led to statistically significant misfit ($\Delta\chi^2$ = 355.197; 156; n = 25,000; p < 0.01), indicating bias as a function of income and educational attainment. Item-level analyses showed that 14 equality constraints led to misfit. Table 1, which provides the parameters for the final model, details the differences across the groups. Model 2b relaxed the misfitting constraints. Model 3 modified Model 2b to constrain the loadings to equivalence across groups. This examined whether the items provided similar reliability and related similarly to alcohol dependence across Whites, Blacks, and Hispanics, after accounting for bias due to income and educational attainment. Constraining the loadings resulted in statistically significant misfit ($\Delta\chi^2$ = 94.646, 52; n = 25,000; p < 0.01) indicating bias as a function of race/ethnicity. Analyses indicated that five equality constraints led to the misfit (see Table 1). Model 3b relaxed these constraints. Model 4 modified Model 3b to constrain the thresholds to equality across Whites, Blacks, and Hispanics. This examined whether affirmative item endorsements had similar likelihoods across race and ethnicity. Constraining the thresholds resulted in statistically significant misfit ($\Delta\chi^2$ = 280.608, 52; n = 25,000; p < 0.01), indicating bias. Analyses showed that 17 equality constraints led to misfit (see Table 1).

The final model relaxed these constraints. Summarily, analyses revealed statistically significant bias across race, ethnicity, income, and education.

Table 1. Final Partially Invariant Measurement Model *(bolded values correspond to statistically significantly different values across groups)*

	WHITES				BLACKS				HISPANICS			
ITEM	Loadings	Thresholds	Income's Effect	Education's Effect	Loadings	Thresholds	Income's Effect	Education's Effect	Loadings	Thresholds	Income's Effect	Education's Effect
Usual number of drinks had less effect	1.301	–2.662	0	0	1.301	–2.662	0	0	1.301	-2.662	0	0
Needed to drink more to get desired effect	1.975	–4.141	0	0	1.975	–4.141	0	0	1.975	-4.136	0	0
Drank equivalent of fifth of liquor in one day	1.110	–2.862	0	0	1.110	–2.862	0	0	1.11	-2.876	0	0
Increased use to get desired effect	2.006	–4.563	0	0	2.006	–4.563	0	0	2.006	-4.516	0	0
More than once wanted to stop or cut down	1.109	–2.033	–0.067	0	1.109	**–1.686**	0	0	1.109	-1.911	0	**0.168**
More than once tried unsuccessfully to stop or cut down	1.253	–3.490	0	0	1.253	**–3.071**	0	0	1.253	**–3.139**	0	**0.285**
Ended up drinking more than intended	2.033	–2.860	–0.081	**–0.108**	2.033	**–3.079**	0	0	2.033	**–3.453**	0	0
Kept drinking longer than intended	**2.103**	–3.181	–0.117	0	**1.790**	–3.181	0	0	2.103	**–3.806**	0	0
Trouble falling asleep when alcohol's effects wore off	**1.083**	–2.563	–0.129	**–0.298**	**1.225**	**–3.082**	0	0	1.083	**–2.91**	0	0
Shook when alcohol's effects wore off	1.52	–3.839	0	**0.008**	1.52	**–4.327**	**0.739**	0	1.52	–4.065	0	0
Felt anxious or nervous when alcohol's effects wore off	1.666	–3.986	0	0	1.666	**–4.477**	**1.186**	0	1.666	–4.213	0	**0.278**
Nausea when effects of alcohol wearing off	1.262	–2.146	0	**–0.083**	1.262	–2.146	**0.008**	0	1.262	–2.274	0	0
Felt unusually restless when alcohol's effects wore off	1.416	–3.155	–0.064	0	1.416	**–3.381**	0	0	1.416	–3.217	0	0
Sweat/heart beat fast when alcohol's effects wore off	1.268	–2.997	–0.085	0	1.268	–2.997	0	0	1.268	**–3.33**	**–0.126**	0
See, felt, heard things when alcohol's effects wore off	1.089	–3.809	0.272	0	1.089	–3.809	0	0	1.089	–3.886	0	0
Had fits or seizures when alcohol's effects wore off	1.037	–4.510	0	0	1.037	–4.51	0	0	1.037	–4.652	0	0
Had bad headaches when alcohol's effects wore off	1.160	–1.846	–0.046	**–0.172**	1.16	**–2.193**	0	0	1.16	–1.928	0	0
Drank or used drugs to get over alcohol's bad effects	1.152	–3.055	0	**–0.108**	1.152	–3.055	0	0	1.152	–2.998	0	0
Drank or used other drugs to avoid getting over alcohol's bad effects	**1.224**	–3.489	0	0	1.224	–3.489	0	0	**1.224**	**–3.574**	0	0
Spent lot of time drinking	1.633	–3.787	0	0	1.633	–3.787	0	0	1.633	–4.1	**–0.15**	0
Spent lot of time getting over drinking's aftereffects	1.466	–4.206	0	0	1.466	–4.206	0	0	1.466	–4.286	**–0.163**	0
Gave up or cut down important activities to drink	**2.344**	–6.215	0	0	**3.88**	**–10.325**	0	0	**2.344**	**–6.21**	0	0
Gave up or cut down pleasurable activities to drink	2.548	–6.949	0	0	2.548	–6.949	0	0	2.548	–6.874	0	0
Continued to drink though made depressed	1.766	–4.433	0	0	1.766	–4.433	0	0	1.766	–4.485	0	0
Continued to drink even though causing health problem	1.284	–3.271	0	0	1.284	–3.271	0	0	1.284	–3.388	0	0
Continued to drink despite prior blackout	1.404	–3.427	–0.063	0	1.404	**–3.889**	0	0	1.404	–3.667	0	0
Found could drink less than before to get desired effect	0.567	–1.369	0	0	0.567	–1.369	0	0	0.567	–1.546	0	0
Alcohol Dependence Factor Mean			0				0.019				**–0.180**	
Alcohol Dependence Factor Variance			1				1.042				1.022	

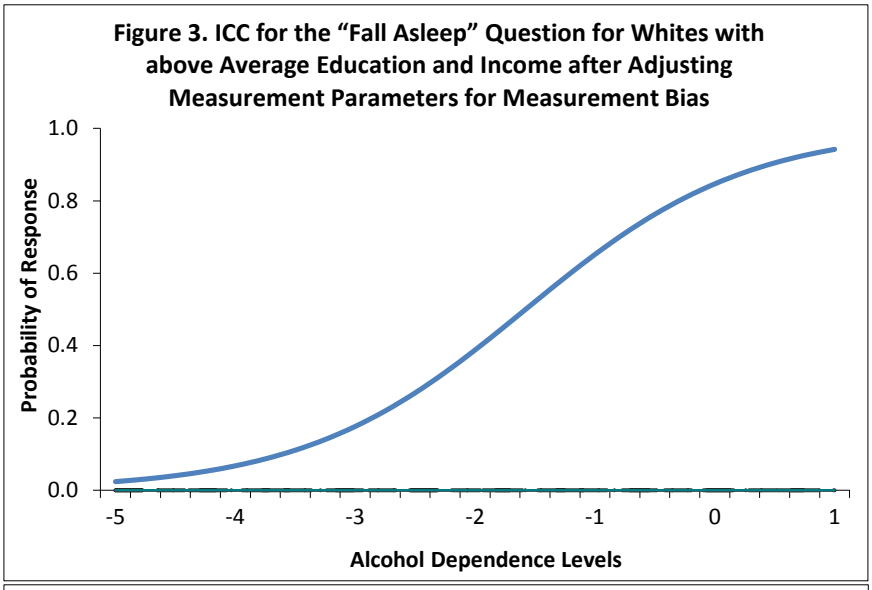


Figure 3. ICC for the "Fall Asleep" Question for Whites with above Average Education and Income after Adjusting Measurement Parameters for Measurement Bias
Probability of Response
1.0
0.8
0.6
0.4
0.2
0.0
-5
-4
-3
-2
-1
0
1
Alcohol Dependence Levels

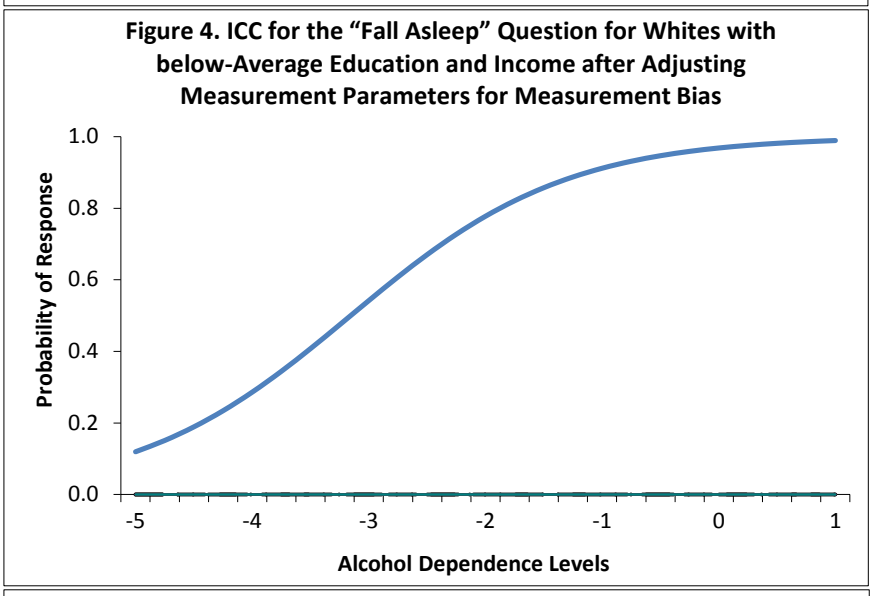


Figure 4. ICC for the "Fall Asleep" Question for Whites with below-Average Education and Income after Adjusting Measurement Parameters for Measurement Bias
Probability of Response
1.0
0.8
0.6
0.4
0.2
0.0
-5
-4
-3
-2
-1
0
1
Alcohol Dependence Levels

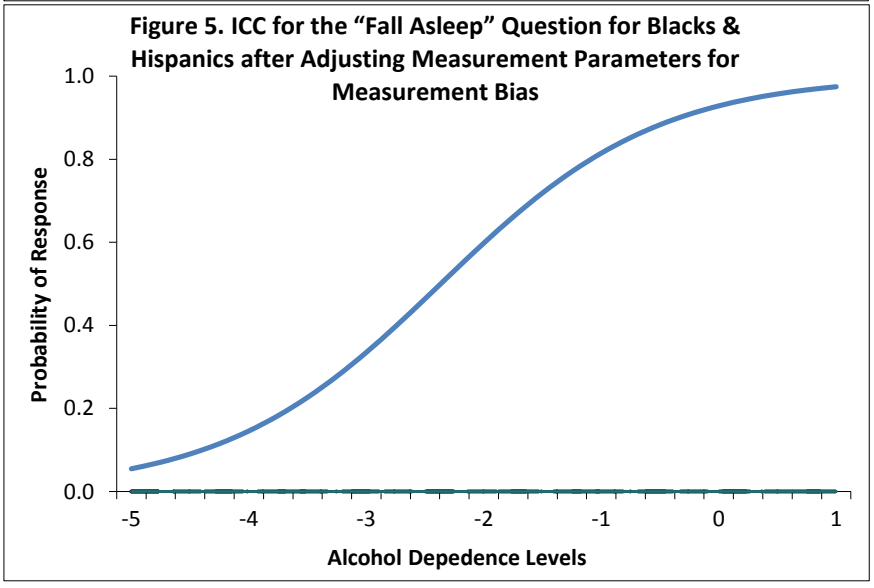


Figure 5. ICC for the "Fall Asleep" Question for Blacks & Hispanics after Adjusting Measurement Parameters for Measurement Bias
Probability of Response
1.0
0.8
0.6
0.4
0.2
0.0
-5
-4
-3
-2
-1
0
1
Alcohol Depedence Levels

Figures 3 though 5 graphically demonstrate examples of the influence of bias on responses. They present the ICCs across Whites, Blacks, and Hispanics for the "Trouble falling asleep" question. Figure 3 gives the ICCs for Whites above average income and education. Figure 4 gives the ICC for Whites with below average income and education. Because these variables did not directly influence measurement for Blacks and because the ICCs did not differ visually for these groups, Figure 5 presents a single ICC for these groups. As seen, bias most visibly influences measurement when respondents will likely to say "No" to the question. As the figure reveals, Whites with above average education and income are more likely to say "Yes" to this question than Whites with below average education and income, Blacks, or Hispanics. This group is only 1.5 standard deviations below mean dependence levels before they will likely endorse the question, as opposed to the others who are not likely to endorse the question until they are nearly 3.5 standard deviations below mean dependence levels.

4.3 Mitigating Measurement Bias

The presence of significant bias indicates that one should not use unadjusted scores to measure alcohol dependence. Rather, one should use model-based estimates of alcohol dependence levels to mitigate systematic error. I compared model-based estimates that resulted from the final model incorporating measurement differences to estimates that resulted from a model ignoring bias. Under the model ignoring bias, Whites served as the reference group and had a mean of zero (for statistical identification). Both Blacks and Hispanics had greater means
($M_{Black} = -0.07 : z = -2.86$; $M_{Hispanic} = -.211 : z = -8.88$), than Whites where negative values reflect more use. However, under the model mitigating bias, Blacks no longer differed significantly from Whites
($M_{Black} = 0.019 : z = 0.28$) and, while Hispanics still had greater alcohol dependence levels
($M_{Hispanic} = -0.18 : z = -2.325$), the disparity was somewhat smaller.

5. DISCUSSION

In this study, I sought to provide an example of how measurement models can provide an empirically informed method of meeting some of the challenges facing health survey research methodologists. I aimed to show how to use an SEM-based model (MG-MIMIC) to evaluate internal validity. And, I aspired to show the importance of empirically evaluating measurement bias. Additionally, I sought to demonstrate how bias can influence analytic results and how model-based techniques can mitigate this.

5.1 Addressing the Challenges

In the current example, results supported the notion that one can create a summary score of severity from these questions. Individuals lower on this score will have greater levels of alcohol use behavior related to dependence. Second, income, educational attainment, and race and ethnicity all directly influenced alcohol dependence measurement. Without accounting for this bias, one would conclude that Hispanics and Black demonstrate significantly greater amounts of alcohol dependence behavior than Whites. However, after using model-based estimates that corrected for bias, model-based estimates clarified that only Hispanics demonstrate lower amounts of alcohol dependence behavior in comparison to Whites and that Blacks do not differ significantly from Whites. These findings highlight that research must consider whether group differences (or similarities) reflect true differences or result from bias.

5.2 Limitations & Additional Challenges

First, stakeholders often require dichotomous indicators. The method for combining and dichotomizing the aggregate all affect reliability and validity. Health survey research has not sufficiently attended to this. Carle et al. (in press) describe model-based methods for creating and evaluating cut-points. Second, the validity of developing contextual-level measures using individuals' self-reports remains relatively unexplored. For example, how can (or should) a set of responses describing contextual aspects of an individual's environment be used to develop a contextual-level measure? Multilevel (ML) SEM uses individuals' responses to estimate contextual-level variables (Lüdtke et al., 2008; Muthén, 1991). This approach explicitly recognizes that individuals' responses include measurement error. In essence, ML-SEM capitalizes on the aspects of using model-based estimates of reliability as described above and generalizes them to the ML setting.

Third, survey research organizations often must make decisions about the number of questions to include. For example, while it may be ideal to include 27 questions, respondent burden may require a smaller set. By using the measurement parameters from the full question set, a methodologist could make an empirically informed choice about which questions to include. The parameters allow methodologists to target the construct levels of interest and maintain reliability. Finally, investigators should always seek to demonstrate external as well as internal validity. External validity refers to whether a set of questions actually measure the construct they purport to measure (McDonald, 1999). Though a description falls beyond this paper's scope, SEM-based measurement work also can address external validity (Bollen, 1989).

It is worth mentioning some of this study's limitations. First, the NESARC did not include a gold standard against which to compare individuals' responses. Responses may not validly reflect individuals' true experiences. Second, NESARC estimates and models are sample-based. These data may not accurately reflect the population. Finally, the cross-sectional nature of the data and lack of random assignment limit causal conclusions regarding the influence of the variables included in the analyses.

5.3 CONCLUSION

In sum, health survey research faces a number of challenges with respect to measurement quality. Model-based methods provide a powerful conceptual and analytical framework for addressing these challenges. They provide an empirical scaffold for addressing reliability and validity, for evaluating the extent to which measurement bias influences efforts to evaluate health statuses across subpopulations, provide a method for more validly aggregating individuals' responses into contextual measures, and deliver an empirical approach to evaluating the reliability and validity of cut-points based on sets of questions. Importantly, model-based methods offer a tool to simultaneously investigate and mitigate bias. Hopefully, future work will see these methods more frequently integrated in health survey research.

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SESSION 1 DISCUSSION

Graham Kalton (Westat)

The five papers in this session address the highly important issue of improving the survey measurement of various aspects of health status and health behaviors. I start by reviewing the standard model for measurement error and the methods that can be used for assessing the effects of measurement errors on survey estimates, and then, in line with the treatment provided by Carle, I will discuss the need for more elaborate models and assessment methods. I will then consider the use of measurement scales and discuss specific aspects of the papers.

The basic model for measurement errors in survey responses dates back to Hansen, Hurwitz, and Bershad (1961) and is discussed in the first edition of Cochran (1963). The model assumes that conceptually, the survey questioning could be repeated over an infinite number of equivalent trials that employ identical survey procedures under the same essential survey conditions. A sampled person may give different responses to the different trials. The basic response error model is then

$$y_{it} = \mu_i + \beta_i + e_{it}$$

Where y_{it} represents the response of individual i on trial t, μ_i is the true value for individual i, β_i is the individual response bias for individual i, $(\mu_i + \beta_i)$ is the average response of individual i over all the conceptually repeatable trials, and e_{it} is the random deviation from this average response on trial t. This general model thus expresses an individual's response on a given trial as the sum of the individual's true value, the individual response bias, and a deviation specific to that particular trial. Under this general formulation, both the individual bias and the individual response variance (the variance of the deviation terms) may be different for each individual. The bias in the estimate of the overall population mean is the average of the individual response biases $(\sum \beta_i / N)$, where N is the population size and the overall response variance is the average of the individual response variances $(\sum V_t(e_{it})/N)$.

Various simplifying assumptions often are made within this general model. One common type of assumption is that the response errors are simply random measurement errors. In this case, sample means are unbiased. It is important to note, however, that correlations with other variables are attenuated, as are regression coefficients when the variable in question is a predictor variable. There also is a loss in the precision of the various estimates. Reliability (re-interview) studies often are used to assess the extent of random measurement errors in pilot studies (as in the pilot study for the National Health and Aging Trends Study [NHATS] described by Kasper et al.) and sometimes also in ongoing surveys (e.g., the Current Population Survey). Given the effects of random measurement errors on measures of relationships between variables, I believe that reliability studies could usefully be conducted more often in conjunction with the main surveys, where operational conditions are likely to be different from those applying in pilot studies. As Carle notes, it is also useful to analyze reliability for subgroups since it may vary across them.

A variant of the completely random response error model assumes that interviewers affect responses so that the random deviations are correlated for the set of respondents interviewed by the same interviewer. Interviewer variance studies that randomly assign sample cases between interviewers are used to examine this form of correlated error (often with restricted random assignment for ease of implementation). Again, I think that greater use could be made of this type of study.

Unless individual response biases cancel out in the aggregate, they lead to a bias in the sample mean. Validity studies, with an external "gold standard," may be used to examine response biases. Researchers

often assume that the average bias is the same for different subgroups of the sample or across time for a repeated survey. This assumption provides the justification for the commonly made, convenient argument that, even though sample means may be biased, differences between subgroup means or means over time are unbiased. However, as Carle notes, this assumption is highly questionable and deserves to be viewed with much greater skepticism. The assumption is of particular concern in the growing area of multinational surveys, where both attaining translation equivalence and cultural differences present severe challenges. Furthermore, there are within-country cultural and linguistic differences to consider.

Maitland et al. provide a good discussion of the challenges in achieving measurement equivalence in health measures such as anxiety across a very diverse set of countries. Their approach started with cognitive interviews in each country around four basic questions about the respondents' experiences of anxiety. These interviews provided some valuable insights into how respondents interpreted the questions, and then questions about these interpretations were added to the field tests conducted in each country. The results demonstrate the difficulties in making cross-national comparisons. For example, the variability in the reported rates of what Maitland et al. classify as impairments, limitations, and pathology is extremely large and highly unlikely to reflect the true variability, thus making cross-country comparisons very questionable. The paper does an important service in demonstrating that one should not naïvely compare the simple frequency rates across countries and in describing an approach for understanding the findings. However, it still leaves open the taxing question of how to make valid cross-country comparisons. In some situations, another line of attack would be to conduct a study using anchoring vignettes to investigate variability across countries in the response scales used by respondents, as has been done for a number of outcomes across countries and across socioeconomic groups (e.g., Chevalier & Fielding, 2011; King, Murray, Saloman, & Tandon, 2004; van Soest, Delaney, Harmon, Kapteyn, & Smith, 2011). The use of focus groups early in the questionnaire design process and the recordings of field test interviews, using computer-assisted recorded interviewing (CARI) where possible, also could be informative.

Since measurement scales have been developed for many aspects of health, it is not surprising that several of the papers discuss the application of such scales in health surveys. Carle points to the value of item response theory (IRT) models for developing and assessing scales for health survey research. These models are widely used in surveys of educational attainment. See, for example, the National Center for Education Statistics (2009) for a description of the IRT models used in the National Assessment of Educational Progress (NAEP). As Carle points out, analyses of differential item functioning (DIF) with such models have the important benefit of being able to identify subgroups of the sample that respond differently to specific items (e.g., subgroups defined by socioeconomic or racial characteristics, or by country in multinational surveys).

A problem that frequently occurs in the application of existing health scales in surveys is that the full scales are too long for easy administration. The most common approach for reducing respondent burden is to cut the scale length by carefully choosing a subset of the items that retains high reliability. Cronbach's alpha coefficient of reliability often is used in selecting scale items and in assessing the reliability of the reduced scale. When there are many scales to be administered, another approach for reducing respondent burden is to give a different subset of scales to different subsets of respondents. This can be done to ensure, for example, that all pairs of scales are administered to selected subsets of respondents. However, this approach results in a reduction in the respondent sample size for each scale. In their paper, Johnson et al. describe applying yet another approach uncommon in health surveys but widely used in education surveys such as the NAEP. This planned missing design, also known as matrix sampling and the split or partial questionnaire design, administers subsets of scale items to subsets of respondents in a balanced randomized

way. Multiple imputation is then widely used to assign values for unasked items. For example, in NAEP, each student receives only two of a possible ten booklets of test items, markedly reducing the burden on the students yet still covering a large number of items across the sample; five values, termed plausible values, are imputed for each missed item. In the field of health surveys, Thomas and colleagues (2006) evaluate the use of matrix sampling for the National Health and Nutrition Examination Survey (NHANES).

The matrix sampling approach clearly reduces respondent burden, but that benefit needs to be balanced against the added analytic complexity. First, there is the need for careful specification of the imputation models, which need to incorporate all variables relating to subclasses for which estimates are required; otherwise, the subclass estimates will be biased. This requirement presents a problem for public use data sets since not all the subclasses of analytic interest can be foreseen. Also, as Johnson et al. discovered, there is a risk of context effects affecting the responses, with a respondent's answer to one item depending on whether the respondent was asked another item. This interesting finding is a warning for the use of matrix sampling since context effects are not that uncommon (Schuman & Presser, 1981). Second, the reduced respondent burden is shifted to the analysts who need to apply multiple imputation variance estimation procedures in their analyses. Researchers need to consider these issues in deciding whether it is necessary to collect some responses for the full range of items across subsamples of respondents or whether a carefully selected subset of items asked of all respondents will better serve their needs.

As discussed in this session, Gfroerer et al. used the more common approach of reducing the number of items in their scaling: they reduced the number of items in the World Health Organization Disability Assessment Scale (WHODAS) from 16 to eight based on an IRT analysis for use in the Mental Health Surveillance System incorporated in the National Survey on Drug Use and Health (NSDUH). They also used Kessler's K6 scale. To develop a classification of whether a survey respondent had a serious mental illness, a sample of respondents was assessed using a standard clinical diagnostic interview (the SCID), with a SCID score of 50 or less being classified as a serious impairment. This classification was then taken to be the "gold standard" and used as the dependent variable in a logistic regression, with the scores on the reduced WHODAS and K6 scales as predictors. The results suggest that the regression fit may not have been that strong, which could have occurred because the predictors were not strong and/or because the "gold standard" was imperfect. Since "gold standards" are rarely perfect, it is useful to conduct evaluations of such measurements—for example, by conducting reliability studies and perhaps interviewer variance studies. For classification purposes, a cut point was determined on the predicted values so that the estimate of the rate of serious impairment from the predicted values agreed with the rate determined from the SCID for the full sample. This cut point was found to be 0.27, so that anyone with a predicted probability of over 0.27 was classified as seriously impaired. It thus appears that many individuals were misclassified and more so in the case when the same approach was used to predict "any mental illness" where the cut point was 0.024. High levels of misclassification raise serious concerns about the quality of the estimates for subgroups of the sample, where the predicted estimates may well diverge from the "gold standard" subgroup estimates. See, for example, the subgroup results reported by Aldworth et al. (2010) for the Mental Health Surveillance System classification. This problem arises in large part because of the common desire in health survey research to classify persons as either having or not having a health condition, whereas in practice it is often the case, as here, that they fall somewhere along a continuum for that condition.

The paper by Kasper et al. describes the experience of using in-home performance tests of physical and cognitive capacity in the pilot study for the NHATS.[6] The growing interest in the use of performance tests in survey research rather than relying solely on respondents' reports is an important development because in many areas, respondents' reports of their capacities can be highly subjective, not reflecting reality. However, as Kasper et al. discuss, conducting performance tests in an in-home survey setting faces significant operational challenges. Thus, it is not a simple step to add performance tests to regular interviews. Since self-reports will therefore remain the means for collecting information about respondents' capacities in most surveys, it is important that those surveys conducting performance tests also collect self-reports as a bridge to the data collected in other surveys. Although performance tests avoid the potential reporting biases of self-reports, it needs to be recognized that the data they provide are not error-free. It is valuable to conduct reliability studies to establish the extent to which a person's performance changes from one administration to another, as was done in the NHATS pilot study (see Freedman et al., 2011, for the results). Also, given the demands on the persons administering the tests, it would be useful to conduct tester (interviewer) variance studies. An attraction of performance tests over self-reports is that the findings should be more comparable across cultural groups and countries.

In summary, among other things, this session highlighted for me the following the measurement issues in health survey research:

- The assumption that responses in health surveys are comparable across different segments of the target population and across countries in multinational surveys should not be adopted uncritically. More research is needed to examine the validity of the underlying constant bias assumption, and more effort is needed to develop well-tested instruments that do yield comparable results for the segments of interest.
- More research is needed to develop effective, easily administered techniques for obtaining clinical assessments and performance measures in in-home survey settings. Assessing and reducing the magnitude of the measurement errors in clinical assessments and performance measures also warrants greater attention.
- With the ongoing expansion in the number of health-related scales for application in clinical settings, there will continue to be a need to adapt these scales for survey settings. The benefits and costs of alternative methods for doing so need to be examined on a case-by-case basis.
- And, in all the measurement error research, the advances in techniques of statistical analysis that have been made in the recent past can usefully be more widely exploited.

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SESSION 1 SUMMARY

Karen CyBulski, **Anne Ciemnecki**, and **Karen Bogen** (Mathematica)

INTRODUCTION

William Arthur Ward, an American scholar, author, editor, pastor, and teacher, said, "The pessimist complains about the wind; the optimist expects it to change; the realist adjusts the sails." As survey methodologists, we are the realists of the research community, and this was a session about adjusting sails. The onus is upon us to measure progress toward our nation's public health goals. It seems that every day we are asked to do our work faster, more cost-effectively, and more accurately than ever before. This session addressed adjusting sails by using tests rather than self-report of functional performance; adjusting by reducing respondent burden by using planned missing data designs; adjusting for cultural differences by understanding the response patterns of different cultures and seeking ways to standardize them (through biomeasures or response to vignettes); and adjusting by using modern test theory and related measurement models such as item response theory, confirmatory factor analysis, and structural equation-based models that provide empirical assessments of questions' psychometric properties to make empirically based decisions about the quality of our measurements.

AGENDA FOR FUTURE RESEARCH

- How does performance testing of functional and cognitive abilities differ from self-reported abilities in the elderly?
- What errors are inherent in performance tests of functional ability?
- How can researchers determine and analyze the reasons for missing performance test data?
- Can self-reported data and performance test data be used together for validity?
- What are the impacts of performance tests on future participation in interviews?
- How does one balance the competing demands of cost, timeliness, accuracy, and burden of data collection?
- How can we be sure that when we reduce respondent burden we are not creating more analytic complexity and cost? That is, how can we avoid replacing respondent burden with analyst burden?
- How can we standardize differences in responses that are the result of cultural norms?
- Are biomarkers and vignettes useful tools? This is especially important as new immigrants enter our nation and our society becomes more diverse.
- How can we, as survey researchers, use modern measurement theory to address the challenges we face as we measure constructs indirectly?
- How can these mathematical models help us (1) address reliability and validity, (2) evaluate the extent to which systematic measurement error influences health statuses across subpopulations, (3) provide a method for more validly aggregating individuals' responses into contextual measures, and (4) deliver an empirical approach to evaluating the reliability and validity of cut points based on sets of questions?

RAPPORTEUR NOTES

After the five papers were presented and the discussant commented on the papers, the floor discussion focused on four main themes: (1) potential errors in performance tests of functional abilities, (2) shifting burden from the respondent to the survey management and analysis staff, (3) enhancing our understanding of cultural differences, and (4) a deeper understanding of how to mitigate against context effects.

Potential errors in performance tests of functional abilities. The early part of the discussion focused on the Kasper paper *Advances in Survey Assessment of Disability in Older Adults: Measuring Physical and Cognitive Capacity in the National Health and Aging Trends Survey*. The discussion compared self-report data on functional ability with data collected through observations and performance tests. Participants in the discussion pointed out that performance tests (1) are not necessarily objective and (2) not only have missing data, but the reasons for the missing data vary and must be understood by those who analyze the performance test data. As survey researchers, we legitimately question the objectivity of self-reported physical-functioning data. Respondents may report about functions they think they can—but actually cannot—accomplish. Do they know for sure that they can carry a ten-pound bag of groceries, when they never carry bags of groceries? Self-reported data are subject to the perception of the reporter. Walking five city blocks might be "good" for a respondent who used to run marathons. Another respondent might consider walking 50 feet "good." A third respondent might report her ability to walk 50 feet "excellent" but have no conception of how far 50 feet is.

Like self-reports, performance tests are subject to their own form of random and systematic errors. One cognitive test asks for today's date. Though instructed not to use a memory aid, respondents could look at watches with date functions or at calendars that are in sight. Although interviewers are supposed to record the use of such recall aids, they might not notice that the respondent relied on an aid. Knowing to consult the recall aid to recollect an unknown date is not the same functional response as not knowing the date and not having the cognitive context or anchor with which to find it.

Understanding missing data is important for interpreting performance test results. Reasons for missing data vary: the respondent could refuse to perform the function, there could be a lack of room in the respondent's dwelling to conduct the performance test, or the interviewer could assume it would be unsafe for the respondent to perform the test and skip over that performance measure. Interviewers must balance a respondent's ability to perform a measure based on how the respondent looks, while at the same time not asking a respondent to perform a physical task that could bring him or her harm.

Performance tests, particularly cognitive tests, change the nature of the interviewing experience. Performance measures (and collection of biomarkers) make the experience more interactive and build rapport between the interviewer and the respondent. On one hand, they break the monotony of the interviewer asking questions and the respondent answering. On the other hand, they may involve the interviewer "touching" the respondent, which might make the respondent uncomfortable. Administering cognitive tests is particularly uncomfortable for the interviewer if a respondent with diminished capacity asks how he or she performed. We have not tested the impacts of performance measurement on future survey participation. These measures have also changed our perspectives as data collectors. We can no longer say, "There are not right or wrong answers to these questions," and we must be diligent about obtaining informed consent for the performance testing.

In light of this discussion, one participant reminded us that there are some objective data that can be validated from other sources. He pointed out that, in principal, one can verify voting behavior from voter

registration records. Thus, we should be cognizant of the sources of the data we are using and the resources available to validate the data.

Shifting burden. Rebekah Young's presentation of *Planned Missing Data in Designs of Health Surveys* generated a discussion of balancing competing demands of cost, timeliness, accuracy, and burden. Her missing data design saved five minutes of respondent burden, which is not trivial for large samples. It did, however, require more complex programming and analysis, including multiple weights and imputation. Shifting the burden from the respondent to the analyst could incur more cost. The group coined the term *analyst burden* and suggested it might not be a fair trade-off for respondent burden.

Response patterns are subject to cultural norms. Response patterns can vary by the respondent's culture and country of origin. Prevalence rates of mental disorders vary dramatically by country. Cultural norms influence where responses on a scale fall. One presenter suggested that respondents in Asian cultures avoid responding at the extreme endpoints of scales and those from Hispanic cultures are less likely to select a scale's midpoint. A participant wondered if there was a way to use biomeasures such as heart rate, blood pressure, or even an MRI to adjust for these cultural differences in response. He proposed presenting a standard stimulus, mapping how the respondent reacts to the stimulus, and recording biomeasures. Others expressed that although interesting, the methodology lacked promise unless researchers understood the meaning of the biomeasure. If we discover a biomeasure that performs the same across cultures and countries of origin and correlates with the domain we are measuring, it could become an anchor for adjusting responses to scales. Another participant suggested vignettes in a similar fashion. Though neither biomeasures nor vignettes will overcome cultural differences, we should keep exploring them as means of adjusting for cross-cultural differences.

Mitigating against context effects. Participants questioned why we use questions that are sensitive to context effects, and, further, why we use these questions to create scales. Although we are aware that context effects exist, we do not test for them. In fact, as we add more questions and topics of interest, we increase the likelihood of context effects. Question order matters more. Do performance measures reduce measurement error or add to error based on the context of when and how the measures are introduced? Can we use modern test theory to examine and overcome context effects?

SESSION 2: Monitoring Health Care Reform

ORGANIZERS: Timothy Beebe (Mayo Clinic), **Michael Davern** (NORC), and **Trena Ezzati-Rice** (AHRQ)
CHAIR: Timothy Beebe

Measuring Health Care Reform: Self-Reports of Health Insurance Premium Assistance and Program in Social Surveys

Dianne Rucinski (Institute for Health Research and Policy, University of Illinois at Chicago)

Debates about health care reform raged during the 2008 election and dominated President Obama's agenda his first years in office. The resulting Patient Protection and Affordable Care Act and Health Care and Education Reconciliation Act of 2010, jointly known as the Affordable Care Act (ACA), was more about health insurance than health care. Because the high and escalating cost of health insurance is perceived as a fundamental cause of uninsurance and underinsuance, the ACA contains numerous provisions ranging from tax credits for individuals and small businesses to further expanding Medicaid to lower the cost of coverage. When fully implemented, provisions of the ACA will expand eligibility for existing programs, shift current program participants from existing programs into new programs, create new programs, and provide tax-funded subsidies for purchasing private plans. As designed, the ACA promises to significantly alter health insurance access, premium assistance, and coverage in the United States. In addition, the act offers states considerable latitude in how elements of support may be implemented at the state level; thus, we might expect substantial variability at the state level in terms of program characteristics and eligibility procedures. Accurate monitoring of the reach and impact of ACA will depend on solid survey measurement of health insurance status and premium support.

This paper examines the implications of the ACA on how we measure health insurance coverage and premium support in population surveys. After describing a set of provisions in the ACA that are expected to have consequences for survey measurement of health insurance and premium support, I follow with brief discussion of how three major health and economic surveys measure premium assistance. Next, using data from a recent survey about health insurance coverage, I present data on the extent to which respondents can and do report receiving health insurance subsidies and characteristics of those providing accurate and inaccurate reports. Finally, I suggest an initial research agenda for exploring health insurance premium assistance measurement.

PROVISIONS OF ACA FOR HEALTH INSURANCE COVERAGE & SURVEY RESPONSES

Because uninsured individuals are disproportionately lower income, many provisions of the ACA concern subsidizing the health insurance for lower income individuals and families. Higher income individuals and those in small group markets face affordability problems too because their premium rates are often substantially higher than group market rates. The ACA contains provisions for subsidized premium assistance in these instances as well. Subsidies can take the form of grants, direct expenditures, tax exemptions, tax deductions, and tax credits. The ACA employs several of these approaches to lower the cost of health insurance to the insured or employers of the insured (Table 1).

The ACA subsidies vary considerably with respect to their visibility to the end user, ranging from the most transparent and intentional such as tax credits and tax deductions to the most hidden and passive such as direct grants and expenditures to third parties (i.e., current and former employers and providers). In the case of the former, individuals must actively document and petition for a tax rebate, a tax credit, or a tax deduction. And the deliberate and often onerous steps necessary to establish program eligibility in the cases of Medicaid, Medicare, and hundreds of other state and federal programs may render the fact of these subsidies visible to individuals.

Table 1. Subsidy Provisions in ACA

Effective Date	Provision
9/23/2010	Early retiree reinsurance program will provide direct reinsurance reimbursement to participating businesses for medical claims for retirees age 55 & older who are not eligible for Medicare & their spouses, surviving spouses, & dependents.
1/1/2011	Rebates to employers/individuals if an insurance company's medical loss ratio is less than 85% (large group) or 80% (small group/individual policy).
1/1/2014	Expand Medicaid eligibility for individuals & families up to 133% FPL.
1/1/2014	Sliding fee subsidy for the direct purchase of health insurance policies through health insurance exchanges for families/individuals between 134–400% FPL.
1/1/2014	Tax credit for very small businesses to purchase health insurance for workers through health insurance exchange.

For the latter type of assistance, the end beneficiaries of these subsidies may have no direct knowledge of the amount paid through the subsidy nor the services rendered covered by the subsidy. The assistance does not go directly to them but to a third party. Since respondents can only retrieve what they hold in memory, survey questions about health insurance subsidy or premium assistance must consider the extent to which these subsidies are known or even knowable to recipients. The fact that many employees are not aware of the extent to which their employers subsidize health insurance coverage appears to have motivated one provision of the ACA—that which requires employers to disclose the value of the benefits they provided beginning in 2012 for each employee's health insurance coverage on the employees' annual Form W-2s. Such efforts to make individuals aware of the value of employer-paid health insurance subsidies is but one indication that the challenge for survey researchers in assessing the impact of ACA will be the development of survey tools that accurately capture the existence of subsidies.

The difficulty of accurately measuring health insurance coverage and type of coverage is well established, as is the measurement of publicly sponsored program participation in general. Ample evidence points to a systematic mismatch between survey reports of Medicaid enrollment and administrative records (Blumberg & Cynamon, 1999; Davern, Klerman, Baugh, Call, & Greenberg, 2008; Kincheloe et al., 2006; Lewis, Ellwood, & Czajka, 1998; Pascale, Roemer, & Resnick, 2009; Wheaton, 2007). This finding will not be discussed further here. Rather, I focus on measurement of another type of subsidy—**premium assistance**. I examine this phenomenon in the Health and Retirement Survey (HRS), Medical Expenditures Panel Survey (MEPS), and National Health Interview Survey (NHIS).

APPROACHES MEASURING PREMIUM ASSISTANCE

The HRS, MEPS, and NHIS take similar approaches to capturing premium assistance and are similar in wording of the questions used to explore characteristics associated with premium assistance reports described later in this paper.

The MEPS and NHIS directly ask whether the respondent or another entity pays some or all of the premium. This approach focuses on identifying other entities that may contribute to paying premiums. In neither the MEPS nor the NHIS premium questions are response categories read to respondents, which may prompt recall of premium assistance. Both questions assume that the respondent is aware that the total cost of the premium is higher than the individual portion of the premium the respondent might pay and assume this information is salient to the respondent. Neither the MEPS nor the NHIS includes elements of program eligibility that may help respondents self-identify or prompt recall. Neither notes behaviors in which respondents must engage in order to gain assistance.

MEPS [HX47]

Who {else} pays {some of/for} the premium or cost of this insurance?

FEDERAL GOVERNMENT 1
STATE GOVERNMENT 2
LOCAL GOVERNMENT.....3
SOME GOVERNMENT 4
OTHER.....91 {HX47OV}
REF.....–7 {BOX_31C}
DK .....–8 {BOX_31C}
[Code All That Apply]

NHIS: Who pays for this health insurance plan?

*If government program is reported, probe for Medicare or Medicaid or SCHIP before entering code 7. If government is employer, enter code 2.

01 Self or family
02 Employer or union
03 Someone outside the household
04 Medicare
05 Medicaid
06 Children's Health Insurance Program (CHIP/SCHIP)
07 State or local government or community program

UniverseText: All private health insurance plan

The HRS questions about premium assistance concern private coverage only and follow the specification that the survey is looking for coverage in addition to Medicare, Medicaid, or long-term care insurance. After establishing that the respondent has such private coverage, the respondent is asked how the coverage is obtained and provides options for the respondent. Like MEPS and NHIS, the HRS series directly ask whether the respondent or another entity pays some or all of the premium. It too assumes that the respondent is aware that the total cost of the premium is higher than the individual portion of the premium the respondent might pay and assumes this information is salient to the respondent. Beyond asking about the organization through which the insurance is obtained, the HRS makes no other reference to program eligibility, but asking about the source of coverage may prompt awareness or recall of premium support. In the HRS, response categories are read to respondents, which also may prompt recall of premium assistance.

R10d. How did you obtain this type of health insurance coverage? Was it through your (or your Husband/ wife/partner's) employer or union, or through an organization or what?

CHOOSE ALL THAT APPLY.

(5225)(A1–A3)

R EMPLOYER/FORMER EMPLOYER.....1,
R UNION 2,
SPOUSE/PARTNER EMPLOYER/FORMER EMPLOYER 3,
SPOUSE/PARTNER UNION 4,
OTHER ORGANIZATION 5,
OTHER.....7

R10e. How is this coverage paid for—entirely by you (or your Husband/wife/partner), entirely by your (Husband/wife/partner's) (former) employer or union, or partly by a (former) employer or union, or what?

(5226)

ENTIRELY BY R OR SP/PARTNER 1,
R UNION .....2, —Skip—(5230)
PARTLY BY (FORMER) EMPLOYER OR UNION 3,
OTHER.....7

REPORTING PREMIUM ASSISTANCE

To what extent are respondents able to report receipt of health insurance subsidies? In this section, I report on the results of a 2009–2010 study, conducted for the Illinois Department of Health Care and Family Services (HFS), whose purpose was to assess children's access to private health insurance coverage, parents' and guardians' perceptions of program services, and their experiences in program utilization. Two random samples of respondents—an RDD landline sample with cell phone supplement and a random sample drawn from administrative records—were asked about payment assistance from five sources: employers/unions, professional associations, federal government, state government, and local government. The RDD landline and cell phone supplement sample was drawn to produce population estimates of uninsured children by region and income. The administrative list sample served to explore elements of health care utilization, health status, and other aspects of the All Kids program.

The RDD landline sample with cell phone supplement used an overlapping sample frame design to account for the rapidly changing telephone environment. This was especially important for representing families with children since national estimates indicate nearly one in four children resided in cell-phone-only households at the time of the survey (Blumberg & Luke, 2010). The goal of the landline/cell phone RDD survey was to interview 1,000 knowledgeable respondents (parents and caregivers) from families with children under 18 in Illinois. The landline RDD portion of the sample was stratified by three **geographic** strata (e.g., Cook—the most densely populated and urban county, suburban collar counties surrounding Cook, and the remainder of the state) and three **income** strata measured by ratio of income to the poverty level (under 133% FPL, 134–200% FPL, and over 200% FPL). Incentives were offered to encourage participation in the low-performing strata cells (under 133% FPL and 134–200% FPL). AAPOR Response Rate 1 was 35.9% for the landline RDD sample.

To help compensate for the increasing number of households without landline telephone service, a separate RDD sample of telephone numbers assigned to cellular service was drawn using a Telcordia database. Cell phone interviews were conducted regardless of whether the household had a landline, but only callers with children residing in the respondent's home were included in the sample. The cell phone sample was not screened for income or for region. Incentives were offered to all cell phone respondents. AAPOR Response Rate 1 was 19.9% for the cellphone RDD sample.

For the list sample, a stratified random sample of caregivers with at least one child enrolled in Illinois's All Kids program was drawn from agency administrative records. Thus, all respondents in this sample had at least one child receiving government-subsidized health insurance. The sample was stratified by program type and geography into nine cells. The three program types are All Kids Assist, covering children in families with annual income less than 133% FPL; All Kids Share and Premium Level 1, for children in families with annual income between 133%–150% and 150–200% FPL, respectively; and All Kids Premium

2–8, for children in families with annual incomes over 200% FPL. Members of the sample were excluded if they were residing in an institution.

For the administrative record sample, prenotification letters in English and Spanish were mailed by replicate. The letters addressed to the parent/caregiver named in the administrative record and described the purpose of the study, described the sponsor and the director of study, and encouraged survey participation. The primary contact number provided by caregivers in the records included both landline telephone and cell phone numbers. A small incentive ($10) was offered to all respondents for completing the survey. Interviews were completed for a total of 776 case records. Because there was a lag time between the drawing of the sample and completion of interviews, enrollment on the date of the interview was assessed for each case leading to the elimination of 54 cases or 7% of the cases. The remaining 723 cases were verified as enrolled in the All Kids program at the time of the interview according to administrative records. Eligibility for the survey was established when the contact person(s) listed in agency records was identified in the telephone interview screener. Approximately 41% of the telephone numbers associated with the case records were deemed not eligible because they were disconnected or nonresidential numbers. Only cases in which administrative record contact name was positively affirmed by the survey respondent were included in this analysis. The AAPOR Response Rate 1 for the list sample was 36.5%.

In the All Kids list sample, according to the records, all respondents have children receiving some kind of government-subsidized health care. Families with children in the Assist program pay no premium or co-payments: the premium is fully subsidized jointly by state and federal government. Those in the Share and Premium Level 1 pay nominal premium and co-payments but most of the coverage is subsidized jointly by state and federal government. Families with children in Premium Levels 2–8 pay graduated premium and co-payment amounts based on income, ranging from a $40 premium (Premium Level 2) to a $300 premium (Premium Level 8), and the premiums are subsidized by the state government only.

MEASUREMENT

All respondents were asked a series of questions about health insurance coverage for each family member. **Half** of each sample was asked the following question after a respondent reported having some type of coverage:

> Who else pays some of or all of the premium or cost of this insurance? Is it paid by…?
>
> CODE ALL THAT APPLY
> [IWER NOTE: READ ALL CHOICES]
> 1 Employer/job/union
> 2 Professional association
> 3 Federal government
> 4 State government
> 5 Local government
> 6 No one else helps to pay the premium
> 7 Another source

Those reporting an employer, job, or union helping pay all or some of the cost or premium for the coverage were coded as reporting *employment-based* premium assistance. Those reporting the federal, state, or local government helping pay all or some of the cost or premium for the coverage were coded as reporting *government* premium assistance.

In this analysis, we focus on employment-based and government-sponsored coverage, omitting the uninsured and those with direct purchase policies. Nearly all those with employment-based coverage and

government-sponsored coverage have some level of premium assistance, and for this analysis, I assume that respondents with employment-based coverage or government-sponsored coverage for themselves or for their children have a premium subsidy. This assumption is plausible given that nationwide in 2010, 95% of workers with family coverage benefited from an employer subsidy (Kaiser Family Foundation and Health Research and Educational Trust, 2010). The average worker contribution for family was 30% with the remainder paid by the employer. In this analysis, all respondents with a child enrolled in All Kids had some level of government-subsidized coverage. In Illinois, government-sponsored health insurance subsidies range from 100% of the premium cost to approximately 50% (based on $600 premium for two children).

RESULTS RDD/CELL SAMPLE

Table 2. Proportion Reporting Premium Assistance, by Coverage Type: RDD Sample

	R with at least 1 child with employment-based coverage (*N* = 232)	R with at least 1 child with All Kids coverage (*N* = 214)
Reporting government premium assistance	0.06 (0.04–0.09)	0.63 (0.56–0.69)
Reporting employment-based premium assistance	0.80 (0.75–0.85)	0.12 (0.08–0.16)

Preliminary analyses suggest that neither those with government nor employment-based premium assistance are universally aware of the premium support they receive, but those receiving government premium assistance are *less* likely to report receiving assistance than those with employment-based premium assistance.

In the RDD/cell sample, 80% of the respondents with at least one child enrolled in employment-based coverage reported employment-based premium assistance, while just under two-thirds of those with at least one child enrolled in All Kids reported government premium assistance. The clear majority of those reporting government-subsidized coverage cited state government (84%); few cited federal (14%).

Logistical regression was used to explore characteristics of the respondents reporting different types of premium assistance using Stata 11.0. Logistic regressions were run separately for those respondents with at least one child with employment-based coverage and those with All Kids coverage with the same predictive model with reporting premium assistance as the dependent variables. For the employment-based coverage subsample, "reported premium assistance" was coded one if respondents reported an employer, job, or union paid some or all of the premium. For those in the All Kids subsample, "reported premium assistance" was coded one if respondents reported the federal or state government paid some or all of the premium. In separate logistic regressions, the dependent variables were regressed on a model incorporating marital status (married = 1), race (White = 1), ethnicity (Hispanic = 1), rural residency (rural = 1), presence of working adult in family (at least one working adult = 1), and income.

Among respondents with at least one child with employment-based coverage, none of the potential demographic predictors were related to premium reporting. Among respondents with at least one child with All Kids coverage, Hispanics were less likely to report premium assistance (odds ratio = 0.45, linearized standard error = 0.16, $t = -2.16$, $p = 0.031$), as were respondents with at least one working family member (odds ratio = 0.51, linearized s.e. = 0.17, $t = 1.92$, $p = 0.06$), holding marital status, race, rural residency, and income constant.

RESULTS LIST SAMPLE

To look more closely at the respondents whose children are enrolled in All Kids, we use the All Kids list sample data set. Just about half the sample (49.6%) reported government premium assistance, and more than 92% of those mentioning government support cite state funding assistance, with 4% citing federal sources and 6% citing local government sources.

Logistical regression also was used to explore characteristics of the All Kids list sample respondents reporting premium assistance. Only respondents who reported at least one child enrolled in All Kids were included in the analysis. Reports of premium assistance were regressed on marital status (married = 1), race (White = 1), ethnicity (Hispanic = 1), rural residency (rural = 1), presence of working adult in family (at least one working adult = 1), and program indicator (Assist/Medicaid or Share/SCHIP program type = 1). All Kids program type is highly correlated with family income with families under 133% FPL in Assist/Medicaid, 134–200% FPL in Share/SCHIP, and those over 200% FPL in All Kids Premium Levels 2–8. As noted earlier, each All Kids program type was associated with different recipient-paid premium levels with none paid by the Assist/Medicaid recipients, nominal but low premiums paid by the Share/SCHIP recipients, and higher but based on a sliding fee for the All Kids Premium recipients. Because the Assist/Medicaid and Share/SCHIP recipients pay nominal or no premium, they have been combined into a single category for this analysis. Those paying significantly more for All Kids may be less likely to report premium assistance.

Respondents with a child in the Assist/Share (Medicaid/SCHIP) components of All Kids were more likely to report premium assistance than those with a child in All Kids Premium (odds ratio = 2.34, linearized standard error = 0.98, $t = 2.02$, $p = 0.04$). Holding all other factors constant, the mean respondents with a child in the Assist/Share (Medicaid/SCHIP) components of All Kids had a 59% predicted probability of reporting government premium assistance compared to 37% of respondents with a child in All Kids Premium.

DISCUSSION

In response to a direct question about premium assistance, reports of assistance were more likely among those with employment-based coverage than those with publicly sponsored coverage. While there is room for improvement among those with employment-based coverage, reporting was not systematically associated with marital status, race, Hispanic ethnicity, presence of a working adult in the household, rural residency, or income. In contrast, premium assistance reporting among respondents with All Kids enrollees was significantly lower. In addition, reporting varied by ethnicity, with Hispanics less likely to report. Respondents with children in the Assist/Share (Medicaid/SCHIP) All Kids program were significantly more likely to report premium assistance than were respondents within children in the All Kids Premium 2–8 program. These results suggest that new approaches to measuring government-supported assistance be explored.

If implemented, a central provision of the ACA will expand the Medicaid program to persons with much higher incomes than previously enjoyed in many states. In addition, new subsidies for direct purchase policies based on a sliding income scale will provide premium assistance where none previously existed. Based on the data presented here, we can expect bias in estimates of self-reported participation among those in Medicaid expansion.

The approaches to measuring premium assistance as employed in the MEPS, NHIS, and HRS and analyzed in this study should be empirically compared with alternative approaches in a split-ballot design.

One such approach might be based on a series employed in the HRS for the prescription drug assistance program called Extra Help. The HRS begins by specifying the eligibility target population (Medicare beneficiaries with limited income and resources) and continues by assessing whether the respondent is aware of a program and what the program is supposed to do—deliver extra help for people to pay for prescription drugs. The questions further incorporate aspects of the process and outcome of securing assistance. It asks the respondent about specific necessary behaviors the respondent would have engaged in order to secure coverage—applying for coverage—and asks about the outcome, anticipating the likely scenario that a respondent would not be aware of the application outcome at the time of the survey.

> HRS [N425] Medicare beneficiaries with limited income and resources may qualify to get extra help paying for their prescription drug coverage. Did you know about this program?
>
> 1. YES 5. NO 8. DK 9. RF
>
> GO TO N428 BRANCHPOINT
>
> N426 Did you apply for extra help?
>
> YES 5. NO 8. DK 9. RF
>
> GO TO N428 BRANCHPOINT
>
> N427 Was your application for extra help accepted or denied?
>
> 1. ACCEPTED 2. DENIED 3. STILL WAITING TO HEAR 8. DK 9. RF

The approach can be modified in a number of ways to conform to program eligibility guidelines and tailored to state-specific processes. It can be adapted to nearly all of forms of subsidy permitted under the ACA from Medicaid participation to tax credits or direct purchase subsidies. Currently, questions about Medicaid participation in ACS, MEPS, NHIS, and other surveys do include short descriptions of the Medicaid program and who it is designed to serve. Thus, a few more questions—has the respondent heard about the program, whether the respondent applied for help covering medical insurance, or even what documents were required in support of the application (i.e., "did you have to show your paystub or tax return when you applied?")—might boost reports of premium assistance for government-sponsored premium support.

In the data presented here, employer premium assistance was much higher than government-sponsored, but there was still nontrivial underreporting. A slightly different approach to that suggested for increasing reports of government-sponsored premium support would be needed for increasing premium assistance reporting from employers. For example, a series might start by specifying the eligibility target population (employees), followed by a statement that many employers pay part of employees' health insurance premium as an employment benefit, and then asking the respondent if her or his employer pays a portion of the premium. However, it is possible that the provision of the ACA that requires employers to disclose the value of the benefits they provided beginning in 2012 for each employee's health insurance coverage on the employees' annual Form W-2s might increase reports of employer support by specifying the extent of the subsidy.

The variety of health insurance subsidy options in the ACA and the likelihood that states will develop their own programs and systems for implementing the various provisions require survey methodologists to consider how the subsidy provision is experienced by groups—Medicaid expansion, tax credits, cash subsidies for direct purchase policies—in order to create survey questions that resonate sufficiently with respondents and result in accurate reports.

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Improving the American Community Survey for Studying Health Insurance Reform

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I. INTRODUCTION

The Affordable Care Act (ACA) is expected to lead to substantial increases in health insurance coverage, particularly through both Medicaid and nongroup plans offered through the new exchanges that will be established in 2014 (Elmendorf, 2011). To assess the impacts of the ACA, it will be critical to have valid estimates of how the distribution of health insurance coverage changes at the national, state, and local levels, overall and for different subgroups. While a number of surveys provide national coverage estimates, the American Community Survey (ACS) is the only survey with sufficient sample size to track coverage at the state and local levels on an annual basis. However, prior research suggests that ACS estimates of nongroup are too high and that estimates of Medicaid/CHIP coverage are too low (Turner & Boudreaux, 2010). In this paper, we summarize methods we developed to address misreporting of coverage on the ACS and show how their use appears to produce nongroup and Medicaid/CHIP estimates on the ACS with more face validity.

II. DATA

The American Community Survey (ACS) is an annual household survey conducted by the U.S. Census Bureau.[1] It is uniquely suited to tracking the impact of the ACA because its sample size is many times larger than other surveys used to study coverage and sufficiently large to study local area coverage in all states and to study nongroup coverage, a relatively rare type of coverage. In terms of potential measurement error, it is important to note that it is a mixed-mode survey that starts with a mail-back questionnaire, with follow-up of nonresponders by telephone and, for a subsample, by an in-person interview with the same questionnaire. Interviewers are not instructed to help the respondent by defining concepts and probing for all relevant information as they do in other surveys used to study health coverage (Jones & Cohen, 2007). In 2008, a question was added to the ACS to ask the respondent about coverage of each individual in the household by any of the following types of health insurance or health coverage plans at the time of the survey:

1. Insurance through a current or former employer or union (of this person or another family member)
2. Insurance purchased directly from an insurance company (by this person or another family member)
3. Medicare, for people 65 and older, or people with certain disabilities
4. Medicaid, Medical Assistance, or any kind of government-assistance plan for those with low incomes or a disability
5. TRICARE or other military health care
6. VA [Department of Veterans Affairs] (including those who have ever used or enrolled for VA health care)

[1] U.S. Census Bureau. *American Community Survey*. www.census.gov/acs/www/. Although the survey includes both housing units and group quarters, as well as active duty military personnel, our estimates focus on the civilian, noninstitutionalized population.

7. Indian Health Service
8. Any other type of health insurance or health coverage plan—specify

Overall, the ACS produces uninsured estimates that are similar to other surveys (Boudreaux, Ziegenfuss, Graven, Davern, & Blewett, 2011), but there are concerns about both the nongroup and the Medicaid/Children's Health Insurance Program (CHIP) estimates. It appears that the ACS substantially overstates the prevalence of nongroup coverage. In 2008, according to the ACS, 27.8 million nonelderly had nongroup coverage[2] compared to 16.6 million in the Current Population Survey (CPS), which has been shown to overcount nongroup coverage (Cantor, Monheit, Brownlee, & Schneider, 2007). Moreover, the National Health Interview Survey (NHIS), which we consider to have the most valid coverage estimates (Kenney, Holahan, & Nichols, 2006; Lynch, Kenney, Haley, & Resnick, 2011) has notably lower estimates: 11.5 million[3] for the nonelderly in 2008. The extent of dual coverage involving nongroup coverage on the ACS is also evidence of misreporting: according the ACS, 9.6 million nonelderly have both ESI and nongroup coverage and 1.3 million have both nongroup coverage and Medicaid/CHIP. We suspect that most of these are misclassified (up to as many as about one-third, resulting from a misallocation of write-in responses) (Mach & O'Hara, 2011) because it is unlikely someone would purchase nongroup coverage if they were already receiving coverage through an employer or government.[4] Like other surveys, the ACS estimates fall below administrative counts of children enrolled in Medicaid or CHIP: in 2008, the ACS estimate of Medicaid/CHIP children was 22.7 million compared the administrative count of 27.9 million (the NHIS estimate was 24.1 million).[5, 6] Prior research indicates that confusion is responsible for some of the incorrect reporting of nongroup and Medicaid (Cantor et al., 2007; Lynch & Resnick, 2009, O'Hara, 2009).

III. METHODS

We developed a set of ACS logical coverage edits that are applied if other information collected in the ACS and, for some cases, eligibility status based on state Medicaid/CHIP eligibility rules imply that the sample case had misclassified coverage (Lynch et al., 2011). We build on edit rules used by Census Bureau that add Medicare, Medicaid/CHIP, and TRICARE/military coverage to sample persons with apparent misreported coverage of those types (Lynch, Boudreaux, & Davern, 2010). The primary motivation for using logical coverage edits are findings that people may lack the knowledge to answer technical questions correctly but that correct answers can be derived from other information respondents are able to provide correctly (Tourangeau, Rips, & Rasinki, 2000). Literature on cognitive interviewing demonstrates how official definitions of health insurance often do not map to respondent perceptions but that interviewees are able to indirectly answer the health insurance question by providing the interviewer with information that can be used to infer coverage status (Pascale, 2009). Coverage edits also are considered a reasonable method for improving the validity of estimates from other surveys (Lynch et al., 2011). For example, NCHS uses

[2] Direct estimates are derived from an augmented version of the ACS, the Integrated Public Use Microdata Series (IPUMS), prepared by the University of Minnesota Population Center. The IPUMS differs from the ACS public use microdata sample (PUMS) released by the Census Bureau for 2008 because it reflects the final coverage edits the Census Bureau applies as well as edits to family relationship data (Ruggles et al., 2010).

[3] Authors' calculation.

[4] It is unlikely that someone would find it worthwhile to buy coverage for themselves or another person who also has Medicaid/CHIP. It is also unlikely that someone who is eligible for Medicaid/CHIP would be able to afford to buy coverage.

[5] Authors' calculation.

[6] By contrast to ACS and NHIS estimates, the administrative counts do not include enrollees in state and other non-Medicaid/CHIP public coverage programs.

other information reported about NHIS sample cases to reclassify coverage for at least nine million nonelderly persons.[7] It is also common practice on surveys to draw inferences from multiple questions without actually asking the respondent to try to answer the question of interest. For example, the labor status used in official employment estimates is derived this way.[8]

Our edits use family income, employment, program participation, eligibility status, health insurance coverage, functional limitation, and combinations of other family- and person-level data to check each case for the presence of a scenario implying that the ACS coverage status is incorrect. We apply the rules in the order of our confidence that the situation implies the alternative coverage type, and we recode the case to the implied coverage if it meets the conditions specified under the rule. Tables 1 and 2 summarize the nongroup rules for adults and children and, due to limited space, we refer readers to a previous report for a summary of the Medicaid/CHIP edit rules we developed (Lynch et al., 2011).

IV. RESULTS

The nongroup edits reduce the estimated number of children with nongroup from 6.4 million to 3.5 million in 2009 (Table 1). They shift 3.7% of all children to another coverage status and change the percent with nongroup from 8.1 to 4.5 (results not shown). Overall, the estimate was reduced to .45 of the original estimate, and the reduction was most dramatic among children with SSI (where the derived estimate was 0), TANF (.02 of the original estimate), and SNAP (.03), and non-Hispanic Black children (.23), American Indian/Alaskan Native children (.27), children above the poverty line but less than twice poverty (.31), and poor children (.33). By state, the reduction was greatest in Hawaii (.44) and least in Vermont (.76), with the median being .54 of the original estimate.

The nongroup edits reduce the estimated number of nonelderly adults with nongroup coverage from 18.9 million to 11.6 million. The impact on the coverage distribution was slightly larger for adults compared to kids; editing moved 4.0% of the adult population to another coverage status and reduced the percent with nongroup coverage from 10.2% to 6.3%. Overall, the nonelderly nongroup estimate was reduced to .61 of the original estimate; the reduction was most dramatic among those with SSI (where the derived estimate was 0), SNAP (.15 of the original estimate), cash assistance (.14), and those who are non-Hispanic Black (.38) or American Indian/Alaskan Native (.41). The reduction was least dramatic among 19–25 year olds (.78), many of whom have nongroup coverage through their college. By state, the reduction was greatest in West Virginia (.41) and least in California (71), with the median being 60% of the original estimate.

After editing, the child population with nongroup coverage is higher income (76.9% have incomes more than twice the poverty threshold compared to 67.9% before), more white non-Hispanic (71.3% compared to 64.9% before), and less likely to be in SNAP (0.5% compared to 6.7% before). After editing, the adult population with nongroup coverage is slightly younger (22.4% were under age 26 after the edits compared to 17.6% before) and more White non-Hispanic (77.9% compared to 74.3%).

The Medicaid/CHIP edits increase the number of children with Medicaid/CHIP and no ESI by 2.8 million and increase the Medicaid/CHIP rate from 29.3% to 32.8% in 2009. The vast majority of the edited cases are determined to be Medicaid/CHIP-eligible in our model, and the others are ones that could have

[7] Urban Institute calculation.

[8] See the item on Labor Force Status Recode in the CPS Data Dictionary available at www.census.gov/apsd/techdoc/cps/cpsmar10.pdf

been eligible based on information that our model is not able to take into account (e.g., family income at an earlier point in the year). Editing based on illogical combinations of coverage within a family accounts for most of the impact (1.9 million). Editing based on illogical nongroup, Medicare, or ESI among Medicaid/CHIP-eligible children accounts for about 470,000 cases and editing children flagged with illogical coverage according to the rules we developed, but not found eligible accounts for about 300,000 cases. After editing, the Medicaid/CHIP child population has a fairly similar demographic distribution relative to the distribution based on the unedited data. However, it is slightly more middle income (40.7% with incomes 100–399% of FPL compared to 39.2% before) and has slightly fewer children from SNAP households (50.7% compared to 53.2% before).

The edits increase the number of nonelderly adults with Medicaid/CHIP by 1.4 million. About 1.2 million are from those originally classified as having nongroup coverage and are edited based on there being a combination of low family income, other means-tested program participation, an indication of a disability, Medicaid/CHIP coverage of another family member, and/or no full-time workers in the family who could afford nongroup coverage. The edits did not change the demographic and socioeconomic characteristics of the Medicaid/CHIP adult population in any noticeable ways.

Table 1. Impact of Editing of ACS Private Nongroup (PNG) Coverage, by Edit Rule, U.S. Children (0–19) in 2009

RULE SUMMARY *(in the order in which the rules are applied)*	**ANY Number**	**NONGROUP Rate**
DIRECT ESTIMATE	6,430,207	8.15%
Edited to Medicaid/CHIP based on being eligible & enrolled in Medicaid/CHIP.	5,980,324	7.58%
Edited to TRICARE/military based on parental status.	5,897,509	7.47%
Edited the Medicaid/CHIP based on refinements to Census rules.	5,801,253	7.35%
Edited to Medicaid/CHIP based on eligibility & sibling's status.	5,769,974	7.31%
Edited to Medicaid/CHIP based on eligibility & parental status implying misreported dual PNG-ESI.	5,730,876	7.26%
Edited to Medicaid/CHIP based on being eligible & having a parent edited to Medicaid/ CHIP from PNG for a non-SSI reason.	5,314,163	6.73%
Edited to Medicaid/CHIP based on being eligible & being a minor parent.	5,309,038	6.73%
Edited to Medicaid/CHIP based on being eligible & having implied misreported dual PNG-ESI from not living with parents & being low income or having functional limitation.	5,270,195	6.68%
Edited to Medicaid/CHIP based on being eligible & having no evidence that the family could afford PNG, the PNG is misreported ESI, or the PNG is paid for by someone outside the household.	5,155,673	6.53%
Edited to Medicaid/CHIP based on being eligible, not having misreported ESI, & having SNAP or cash assistance	5,114,464	6.48%
Edited to Medicaid/CHIP based on being flagged as having possibly illogical coverage & being immigrant-eligible & having an indicator of possibly being income-eligible earlier in the year.	5,007,364	6.34%
Edited to Medicaid/CHIP based on being flagged as having possible illogical coverage & being immigrant-eligible & being in a SNAP household with no military coverage.	5,003,762	6.34%
Edited to Medicaid/CHIP based on being flagged as having possibly illogical coverage & being in a SNAP household with no military coverage.	5,003,311	6.34%
Edited to ESI based on having a parent edited from PNG to ESI.	4,113,673	5.21%
Edited to ESI based on having reported ESI & a parent with a full-time public sector job.	3,783,679	4.79%
Edited to ESI based on having reported ESI & a high-income parent with ESI & no PNG.	3,630,719	4.60%
Edited to ESI based on having reported ESI & an unemployed parent.	3,628,776	4.60%
Edited to ESI based on having reported ESI & a parent with a full-time private-sector job & not being poor or in a public program.	3,068,039	3.89%
Edited to ESI based on having reported ESI & a parent with some other type of HIU employment other than self-employment.	2,892,064	3.66%
DIFFERENCE FROM UNEDITED ESTIMATE	**3,538,143**	**4.49%**

Table 2. Impact of Editing of ACS Private Nongroup (PNG) Coverage, by Edit Rule, U.S. Nonelderly Adults (19–64) in 2009

RULE SUMMARY (in the order in which the rules are applied)	ANY Number	NONGROUP Rate
DIRECT ESTIMATE	18,889,778	10.23%
Nonelderly Adult with Nongroup & Medicaid		
Edited to Medicaid/CHIP based on being a parent with Medicaid/CHIP & less than 200% FPL.	18,726,521	10.14%
Edited to Medicaid/CHIP based on having Medicaid/CHIP & a functional limitation.	18,426,736	9.98%
Edited to Medicaid/CHIP based on Medicaid/CHIP with SSI, SNAP, or cash assistance but no minor child.	18,288,821	9.91%
Edited to Medicaid/CHIP based on having Medicaid/CHIP & SSI, SNAP, or cash assistance but income higher than 200% FPL.	18,269,368	9.89%
Edited to Medicaid/CHIP based on having Medicaid/CHIP & SSI, SNAP, or cash assistance but income higher than 200% FPL & no minor child.	18,258,775	9.89%
Nonelderly with Nongroup & Military	17,972,693	9.73%
Nonelderly with Nongroup & Other Employer Coverage		
Edited to ESI based on being a full-time public-sector worker or being the spouse or dependent child of one.	16,801,262	9.10%
Edited to ESI based on being the spouse or dependent child in a high-income HIU with a full-time private-sector spouse/parent with ESI & no PNG.	16,330,960	8.84%
Edited to Medicaid/CHIP based on being a 19- or 20-year old in a low-income HIU (dorms excluded) with program participation & a parent (to avoid selecting college students who don't live at home because they often have PNG through school) but none with nongroup or ESI.	16,330,001	8.84%
Edited to ESI based on having low or moderate income, a functional limitation, & someone in the HIU with employment.	16,267,024	8.81%
Edited to ESI based on having cash public assistance or SNAP & being in an HIU with someone who has a full-time job.	16,184,434	8.77%
Edited to Medicaid/CHIP based on having cash public assistance or SNAP & no one with a full-time job.	16,126,207	8.73%
Edited to ESI based on being an unemployed HIU.	16,047,992	8.69%
Edited to ESI based on having a full-time public-sector worker in HIU & not being poor or in a public assistance program.	13,916,925	7.54%
Edited to ESI based on being in an HIU with some form of non-self-employment.	13,333,775	7.22%
Other People with Nongroup		
Edited to ESI based on having a full-time public-sector worker in HIU.	13,165,343	7.13%
Edited to ESI based on being in a high-income family & having a spouse with ESI & no PNG.	12,618,883	6.83%
Edited to ESI based on being a dependent child in a high-income family with a parent that has ESI & no PNG.	12,569,279	6.81%
Edited to ESI based on being a dependent child with two parents with ESI & one parent with a full-time non-self-employed job & the other with no job.	12,566,536	6.81%
Edited to Medicaid/CHIP based on having a low-income adult & a functional limitation	12,116,304	6.56%
Edited to Medicaid/CHIP based on having a low income & cash assistance or SNAP.	11,897,610	6.44%
Edited to Medicaid/CHIP based on being a citizen with a low income & a spouse or child with Medicaid/CHIP	11,873,164	6.43%
Edited to Medicaid/CHIP based on being a citizen parent with a low income & no public-sector job in the HIU.	11,432,742	6.19%
DIFFERENCE FROM UNEDITED ESTIMATE	**7,457,036**	**4.04%**

The logical coverage edits we apply to the ACS data generally move the ACS coverage distributions closer to the NHIS coverage distributions. Table 1 shows the 2009 insurance coverage distribution of children before and after editing in the ACS compared to the distribution from the NHIS. After editing ACS, its estimated rate of Medicaid/CHIP coverage for children (in a hierarchy after ESI) is 32.8%, which is the same point estimate derived from the NHIS. The majority of the reclassified cases—1.5 million—had

previously been identified as having nongroup coverage, and an additional 0.7 million were reclassified from ESI. After editing, children have lower rates of nongroup coverage (3.6%) that are similar to NHIS (3.4%). For adults, Table 2 shows that after editing, the rate of Medicaid/CHIP is 8.7% compared to the NHIS estimate of 8.9% and the rate of nongroup coverage is 5.6% compared to the NHIS estimate of 5.0%.

Table 3. Coverage Distribution of U.S. Children (0–18) before & after Editing in ACS, Compared to NHIS, 2009

	ACS				NHIS	
	Before		After			
	#	%	#	%	#	%
Total	**78.9**	**100.0%**	**78.9**	**100.0%**	**78.5**	**100.0%**
ESI	44.2	56.0%	43.5	55.1%	42.7	54.4%
Medicaid/CHIP	23.1	29.3%	25.9	32.8%	25.8	32.8%
PNG	4.3	5.5%	2.8	3.6%	2.7	3.4%
Medicare	0.2	0.3%	0.1	0.1%	0.2	0.3%
Uninsured	7.1	9.0%	6.6	8.4%	6.6	8.5%
Other*					0.5	0.6%

Source: Urban Institute analysis of American Community Survey (ACS) 2009 data from the Integrated Public Use Microdata Series (IPUMS). The Urban Institute Health Policy Center's ACS Medicaid/CHIP Eligibility Simulation Model and coverage estimates were developed under a grant from the Robert Wood Johnson Foundation.

Table 4. Coverage Distribution of U.S. Nonelderly Adults (19–64) before & after Editing in ACS, Compared to NHIS, 2009

	ACS				NHIS	
	Before		After			
	#	%	#	%	#	%
Total	**184.6**	**100.0%**	**184.6**	**100.0%**	**184.9**	**100.0%**
ESI	116.8	63.3%	118.2	64.0%	115.7	62.6%
Medicaid/CHIP	14.9	8.1%	16.1	8.7%	16.5	8.9%
PNG	12.7	6.9%	10.3	5.6%	9.2	5.0%
Medicare	1.9	1.0%	1.8	1.0%	2.8	1.5%
Uninsured	38.4	20.8%	38.3	20.8%	39.2	21.2%
Other*					1.6	0.8%

Source: Urban Institute analysis of American Community Survey (ACS) 2009 data from the Integrated Public Use Microdata Series (IPUMS). The Urban Institute Health Policy Center's ACS Medicaid/CHIP Eligibility Simulation Model and coverage estimates were developed under a grant from the Robert Wood Johnson Foundation.

DISCUSSION

As designed, the edits increase the number of children and adults with Medicaid/CHIP and decrease the number with nongroup coverage. The edits add more children than adults to the Medicaid/CHIP population, which is expected given the larger difference between the unedited ACS estimates and the NHIS estimates for children compared to adults. That the child enrollee population is higher income after the edits is not surprising given that record check studies show that higher income enrollees are more likely to be misreported. That the adult enrollee population is similar before and after editing suggests that the sample cases we edit may not be very different from those originally reported as having Medicaid/CHIP.

The impact of the edits on any nongroup coverage is much larger than the impacts on nongroup coverage considered in the context of a coverage hierarchy (after Medicaid/CHIP and ESI) because there is so much dual coverage in the unedited ACS estimates. As expected, there is little dual-nongroup/ESI or dual-nongroup/ Medicaid/CHIP coverage in the child population after editing, because people rarely simultaneously have those combinations of coverage (Mach & O'Hara, 2011). That the child nongroup population is higher income with fewer SNAP households also suggests that the resulting estimates are more valid because low income

people cannot usually afford to buy nongroup coverage (Mach & O'Hara, 2011). There are still 1.1 million individuals with dual coverage in the adult nongroup population after editing, which this suggests that the edits for adults are conservative. That the ACS nongroup estimate is still 1.1 million higher than the NHIS estimate of 9.2 million and has 2.1 million poor people (data not shown) also suggests that the editing is conservative (although some of the individuals classified as poor are likely college students who get nongroup through their school or other young adults who get it from their parents).

CONCLUSION

Coverage edits appear to improve the validity of Medicaid/CHIP and non-group estimates on the ACS. They are an intuitive and inexpensive technique for improving the validity of the ACS coverage estimates. Despite the face validity of the edited estimates, there are a number of outstanding questions that should be addressed in order to confirm that these edits are valid and to further strengthen the validity of the ACS estimates. First, we recommend that the Census Bureau re-interview sample people who look like Medicaid/CHIP enrollees but do not have Medicaid/CHIP reported to assess the validity of the coverage information reported on the ACS. Second, we recommend record-check analysis to assess how well the edits identify enrollees found in Medicaid/CHIP enrollment records. Third, we recommend that the Census Bureau conduct cognitive interviewing to inform improvements to the ACS questionnaire and also provide insights about the dynamics of coverage misreporting and the covariates associated with misreporting. Fourth, we recommend that the Census Bureau re-evaluate how recodes write-in responses to nongroup coverage. Finally, we recommend that the Census Bureau test changes to the instrument aimed at improving the accuracy of the coverage information provided on the ACS.

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Comparison of Estimates of Emergency Department Visits from the Medical Expenditure Panel Survey and National Hospital Ambulatory Medical Care Survey[1]

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INTRODUCTION

The level of emergency department utilization and associated trends are important areas of interest for health services researchers and policy makers. Surveys that contain emergency department utilization data used to analyze such issues may have different objectives and data collection methodologies. Thus, it is important to understand the available data sources and their methodologies in order to correctly interpret data from a given survey or make informed decisions about which survey data set(s) are most appropriate for a particular analysis (Machlin, Valluzzi, Chevarley, & Thorpe, 2001; Machlin & Zodet, 2007). The purpose of this paper is to examine the large differences that occur in estimates of the same use variable (emergency department visits) derived from household vs. provider-based sources of information. The focus is on illustrating important methodological and contextual considerations that can affect analyses when using different surveys for measuring emergency department use.

BACKGROUND

The U.S. Department of Health and Human Services sponsors a number of national surveys that provide data on emergency department use but entail different objectives and methodologies. One of these surveys, the Medical Expenditure Panel Survey (MEPS), collects utilization data through household interviews. In contrast, the National Hospital Ambulatory Medical Care Survey (NHAMCS) collects data from hospitals pertaining to emergency department visits (Machlin et al., 2001). Here we compare 2008 data on emergency department use collected in the MEPS to comparable use data collected in the NHAMCS.

MEPS collects detailed data on health care use, expenditures, and sources of payment by means of its Household Component (HC) and Medical Provider Component (www.meps.ahrq.gov/). The panel design of the HC includes five rounds of interviews that cumulatively cover two consecutive calendar years. At each interview, one adult respondent typically provides information about all persons in the household. The MEPS-HC covers the U.S. civilian noninstitutionalized population. For all emergency department visits and hospital stays reported in the HC, permission is requested to contact the medical provider for additional details. This portion of MEPS is referred to as the Medical Provider Component (MPC). The MEPS-MPC collects information on all hospital events for each person-provider pair included in the survey, whether or not each event is reported by the household respondent.

The NHAMCS is a national probability sample of visits to emergency departments of noninstitutional general and short-stay hospitals, exclusive of Federal, military, and Veterans Administration (VA) hospitals, hospital units of institutions, and hospitals with less than six beds. Within each hospital, all emergency

[1] The views expressed in this paper are those of the authors, and no official endorsement by the Department of Health and Human Services or the Agency for Healthcare Research and Quality is intended or should be inferred.

departments are selected. Patient visits are systematically selected over a randomly assigned four-week reporting period. A visit is defined as a direct personal exchange between a physician or a staff member operating under a physician's direction for the purpose of seeking health care (www.cdc.gov/nchs/ahcd/about_ahcd.htm).

In comparing estimates of emergency department visits for MEPS and NHAMCS, we take several steps to align the population represented and make the bases of the MEPS and NHAMCS statistics as similar as possible (Table 1). For MEPS, alignment involves subtracting visits taking place in a VA facility, while for the NHAMCS, residents of a nursing home or other institution and the homeless are removed. These exclusions result in totals equaling 56.1 million emergency department visits based on MEPS and 120.3 million based on NHAMCS.

Table 1. Aligning Estimates of Total Emergency Department Visits

	MEPS	NHAMCS
2008 total (in millions)	56.8	123.8
Exclude VA facility	0.7	—
Exclude institutionalized, homeless	—	3.5
Total after exclusions	56.1	120.3

Number of Emergency Department Visits, 2008

The estimate from NHAMCS for total visits to emergency departments in 2008 (120.3 million) is approximately double that of the estimates for MEPS (56.1 million; Table 2). The bulk of this difference is attributable to visits where a physician is seen (108.8 million for NHAMCS vs. 52.8 million for MEPS). For both MEPS and NHAMCS, the percent of emergency room visits where a non-physician is reported as having been seen is relatively small (2.3% and 10.9%, respectively).

Table 2. Number of Emergency Department Visits, 2008

	MEPS Estimate in millions (SE)	MEPS Percent distribution	NHAMCS Estimate in millions (SE)	NHAMCS Percent distribution
Total after exclusions	56.1 (1.6)	100.0%	120.3* (6.1)	100.0%
Saw doctor	52.8	94.1%	108.8	89.7%
Saw nondoctor	2.3	4.1%	10.9	9.1%
Unknown	1.0	1.8%	1.4	1.2%

*Significantly different from MEPS ($p < 0.05$).

The comparisons reveal substantial differences between the two survey estimates of emergency department use. These variations are likely due to the interaction of a number of factors, including differences in data collection methodologies, target populations, types of providers and settings covered, and reporting differences. The household survey (MEPS) targets the civilian noninstitutionalized population, whereas the provider survey (NHAMCS) is more inclusive and includes visits from persons outside that population. Differences in reporting of emergency department visits immediately followed by an inpatient admission may explain a small part of this wide variation. Distinguishing an initial emergency department visit from a subsequent hospital stay may not be obvious for MEPS respondents, especially considering the emergency department visit may have been brief relative to the inpatient stay (Machlin et al., 2001). Also, MEPS estimates could result in potential underreporting if persons who use the emergency department as their usual source of care may tend to underreport or misclassify some of these visits as

outpatient department or office-based visits (Machlin et al., 2001). Additionally, what a household respondent in MEPS might consider to be an emergency department visit would not necessarily be consistent with how such visits are classified in the NHAMCS from the provider's perspective. For example, a hospital visit that was initiated in the emergency department but then immediately referred to another department for tests may be reported as an outpatient department visit in MEPS but would be counted as an emergency department visit in NHAMCS (Machlin & Zodet, 2007).

Nonetheless, it is unclear precisely what accounts for the large difference in estimates of emergency department visits between MEPS and NHAMCS. This research is designed to better account for that difference. In this investigation, we obtained the MPC records for all hospital events captured in the provider component of the survey and compared them to household respondent-reported utilization of those hospitals to investigate the possible underreporting or misreporting of emergency department visits in the HC. The objective is to better inform efforts to improve the quality of data collection in both household and provider-based surveys.

METHODS

Research Questions

1. To what extent is the undercount due to underreporting by household respondents?
2. What characteristics of sampled persons are associated with underreporting?

Analytic Sample

The analytic sample is derived from the household respondent's reported hospital events. Once permission is obtained from the household respondent, providers are contacted in order to obtain hospital event records. Cooperating facilities provide medical and billing records for all the sampled person's events. This process produced 4,259 person-hospital pairs in 2008. Of these 4,259 person-hospital pairs, 3,434 have a positive count of emergency department visits in both the HC and MPC. Additionally, there are 825 person-hospital pairs with a positive count of emergency department visits in the MPC but none in the HC.

Once we extracted the analytic sample of 3,434 person-hospital pairs, we compared counts of emergency department visits between the HC and MPC, using the MPC count as the gold standard. We used multivariate logistic models and calculated odds ratios to identify characteristics of persons in the sample significantly associated with accurate reporting and substantial underreporting in the HC.

RESULTS

For two-thirds (66.5%) of the person-hospital pairs, there is perfect agreement between the HC and the MPC in the number of emergency department visits. In addition, 10.7% of the person-hospital pairs have overreporting in the HC relative to the MPC. However, 22.9% of the person-hospital pairs have underreporting: 4.8% pairs with underreporting of two emergency department visits and 4.4% with underreporting of three or more (Table 3).

As a consequence of these differences, the estimate of aggregate emergency department visits varies depending on the data source (Table 4). Using the public use file HC-121 (www.meps.ahrq.gov/mepsweb/data_stats/download_data_files_detail.jsp?cboPufNumber=HC-121), there

were 56.1 million emergency department visits in 2008. The 3,434 person-hospital pairs originating in the HC produce an estimate of 42.7 million emergency department visits. In contrast, using the MPC as the source (for the same 3,434 person-hospital pairs), the estimate is 51.2 million such visits. Also, there are an additional 12.7 million visits that are only identified in the MPC. These are from a very select sample, however. That is, a person who had at least one household-reported hospital event for which the hospital responded in the MPC, and the hospital reported an ER visit that was not reported by the household respondent. Nonetheless, the existence of these unreported visits indicates that underreporting is not limited to undercounting of visits for reported users but also extends to nonreporting of any hospital use.

Table 3. Comparing Counts of Emergency Department Visits among Person-Hospital Pairs

HC-MPC Difference	Percent distribution *N* = 3,434
≤ –3	4.4
–2	4.8
–1	13.7
0	66.5
1	9.0
2	1.2
≥3	0.5

Table 4. Multivariate Logistic Models

VARIABLE	
Dependent Variables	
Accurate reporting: 1 if HC-MPC ED visit count, 0 otherwise	Substantial underreporting: 1 if HC-MPC ≤ –3, 0 otherwise
Independent Variables	
Income	Health insurance status
Marital status	Number of chronic health conditions
Sex	Health limitations
Age	Perceived health status
Race/Ethnicity	Usual location of health care
Original respondent	

Table 5. Estimated Aggregate Emergency Department Visits, by Data Source

Data Source	Estimate (millions)
2008 MEPS-HC (reports for all sample persons weighted)	56.1
HC Analytic Total (3,434 pairs weighted)	42.7
MPC Analytic Total (3,434 pairs weighted)	51.2
MPC Additional (825 pairs weighted where HC ED counts = 0)	12.7

We also constructed two multivariate logistic models to examine characteristics associated with accuracy of reporting. One model represented fully accurate reporting (the HC and MPC counts were equal); an alternative model represented substantial underreporting (the HC count was at least three less than the MPC count). A number of characteristics of the sample person in the person-hospital pair were included in the models: income, marital status, sex, age, race/ethnicity, consistency of respondent during the reference year, health insurance status, number of chronic conditions, presence of health limitations, perceived health status, and usual location of care (Table 5).

Accurate Reporting

Those person-hospital pairs with a doctor's office as the sample person's usual source of care were 2.86 and 1.41 more likely to show accurate reporting compared to those with an emergency department or other hospital department, respectively, as their usual location of care. Person-hospital pairs with privately insured sample persons were 1.52 times more likely to show accurate reporting compared to those with public health insurance. Those in excellent, very good, or good health were 1.59 times more likely to be accurate reporters compared to those reporting fair or poor health. With respect to demographic characteristics, those White (1.96 or 1.39), male (1.32), age 65 and older (1.41), married (1.56), and having a high income (400% or more of the Federal poverty level; 1.84) were more likely to be accurate reporters compared to their respective reference categories (Table 6).

Substantial Underreporting

In contrast to accurate reporters, Asians, Blacks, those in fair or poor health, those with public insurance, and those reporting more than one chronic condition were more likely to be substantial underreporters. Asians and Blacks (4.31 and 1.95) were more likely to be associated with substantial underreporting compared to Whites. Those in fair or poor health were 3.14 times more likely to be substantial underreporters compared to those in excellent, very good or good health. Those with public health insurance were 1.99 times more likely than those with private health insurance to be substantial underreporters. Finally, those having one or more chronic conditions were 1.95 more times likely to be substantial underreporters compared to those with no chronic conditions (Table 7).

Table 6. Accurate Reporting Model (HC-MPC = 0)—Significant Odds Ratios

Significant Odds Ratio	Odds Ratio	Reference Category
Usual location of care is doctor's office	2.86	Usual location of care is hospital emergency department
Private health insurance	1.52	Public health insurance
Excellent/Very good/Good health	1.59	Fair/poor health
Usual location of care is doctor's office	1.41	Usual location of care is hospital, not emergency department
White	1.96	Asian
High income	1.84	Poor
Married	1.56	Widowed
Age 65+	1.41	Age 18–64
White	1.39	Black
Male	1.32	Female

Significantly different from reference category ($p < 0.05$).

Table 7. Substantial Underreporting Model (HC-MPC ≤ –3): Significant Odds Ratios

Significant Odds Ratio	Odds Ratio	Reference Category
Asian	4.31	White
Fair/Poor health	3.14	Excellent/very good/good health
Public insurance	1.99	Private health insurance
Black	1.95	White
One or more chronic conditions	1.95	No chronic conditions

Significantly different from reference category ($p < 0.05$).

DISCUSSION

While it is likely that the HC and MPC will agree on the number of emergency department events (66.5%), two issues emerge from these analyses with regards to household reporting of hospital events. First, there is a greater propensity to underreport (22.9%) emergency department visits than to overreport (10.7%). Second, there is a substantial number of emergency department visits not reported by the household respondent (at least 12.7 million). Characteristics of those identified as substantial underreporters (HC-MPC ≤ -3) are Asian, Black, in poor or fair health, having more than one chronic condition, and having public health insurance.

Taking into account the finding of underreporting and nonreporting partially explains the observed differences in estimates of aggregate emergency department visits between the MEPS and NHAMCS. Still, the observed underreporting and nonreporting does not entirely close the gap between the two surveys. While potential adjustment strategies are not clearly revealed through this analysis, factors that also should be considered include representativeness of the sample, how households vs. providers define an emergency department visit, respondent (who responds for the entire household) vs. sampled person characteristics, and misclassification of events. In addition, instrument redesign could be considered in order to elicit more accurate reporting and minimize the likelihood of underreporting, nonreporting, and misclassification, especially for those respondents with characteristics associated with substantial underreporting.

MEPS and the NHAMCS data sources have unique advantages and disadvantages when used to examine patterns of emergency department visits, making the different data sources appropriate for different applications. For example, MEPS may be better suited for trend analysis or behavioral research, while NHAMCS may be preferable for generating estimates of the aggregate number of emergency department visits. Understanding the design, population coverage, and estimates from each of the data sources is therefore critical to choosing the most suitable data source to study emergency department care. Whether working with one or multiple data sources, it is important for researchers to assess the strengths and limitations of the particular source(s) being used and to use caution when interpreting and comparing estimates (Machlin et al. 2001; Machlin & Zodet, 2007; Owens et al., 2010; Rhoades, Cohen, & Machlin, 2010).

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Assessing the Accuracy of Prescription Drug Purchase Data for Medicare Beneficiaries in the Medical Expenditure Panel Survey[1]

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INTRODUCTION

The Medical Expenditure Panel Survey (MEPS) collects data on health care utilization, expenditures, sources of payment, insurance coverage, and health care quality measures. The survey, conducted annually since 1996 by the Agency for Healthcare Research and Quality (AHRQ), is designed to produce national and regional estimates for the U.S. civilian noninstitutionalized population (Ezzati-Rice, Rohde, & Greenblatt, 2008). In particular, MEPS data has the capacity to support studies of prescription drug utilization and expenditures in the United States. Moreover, these data are widely used by researchers for behavioral modeling and policy simulations. Given the potential for MEPS data to shape national health care policy, the validity of the data is critical.

Information on prescription medicine use in MEPS is collected during household interviews in a series of five rounds. At each round, respondents are asked to enumerate all prescription drug acquisitions and the number of times each drug was obtained for all family members. Annual use counts are derived for each person by summing across rounds in the calendar year. Prescription medicine utilization is measured as (1) the total number of drugs and (2) the total number of drug acquisitions (i.e., number of fills/refills). Additional information about payments for these prescription drugs is collected via follow-back interviews, but this study focused only on the utilization measures (i.e., number of drugs and number of fills/refills). The objectives of this study were to assess the quality of the MEPS household-reported prescription drug utilization data via a matched comparison with Medicare administrative claim records and to investigate whether reporting errors lead to systematic biases in behavioral analyses of the MEPS prescription medicine data.

BACKGROUND

The accuracy of other forms of health care service use in the MEPS has been the subject of various validation studies. For example, in a linked study of MEPS and Medicare claims data, Zuvekas and Olin (2009a, 2009b) found inpatient stays and number of inpatient nights were accurately reported. MEPS respondents, however, underreported office visits by 19%, emergency department visits by 34%, and Medicare expenditures by 12%. Nonetheless, behavioral analyses are not likely to be significantly affected by misreporting, because variation in underreporting across subgroups was small in magnitude even when statistically significant.

Validation studies of reported prescription drug use in other surveys typically find high accuracy but variation across drugs (e.g., Klungel et al., 2000). The accuracy of drug use reporting varies with drug characteristics and amount of drugs used. Other studies report measures of agreement for drug classes and find agreement varies greatly (Nielsen, Søndergaard, Kjøller, & Hansen, 2008.). Most studies have focused on

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people with specific conditions or specific classes of drugs, or validated data collected for specific studies. Poisal (2003–2004) evaluated many measures of use in the U.S. Medicare Current Beneficiary Survey (MCBS) before the Medicare Part D program started. Respondents reported 82.3% of fills or refills found in pharmacy data, but 23% of respondents reported fills not found in the pharmacy data. Apparent overreporting may reflect incomplete pharmacy data or free samples, and Poisal made assumptions about the amount of missing pharmacy data to estimate the accuracy of the MCBS.

METHODS/ANALYTIC APPROACH

Data

We used the Medicare Part D claims as our validation data for this study. The Medicare Part D program began on January 1, 2006. Beneficiaries may obtain Part D coverage through either a prescription drug plan or a Medicare Advantage plan. The Medicare Part D Denominator files indicate the months beneficiaries were enrolled in either of these two plans. The MEPS Prescription Drug Event files contain drug claims from both types of plans.

The MEPS analytic sample was constructed by matching MEPS Medicare beneficiaries to their Medicare administrative data. We selected MEPS Medicare beneficiaries from 2006 and 2007. These MEPS beneficiaries were asked to voluntarily provide their Medicare card number so that their Medicare records could be located and used for statistical research purposes. Summary of the matching process is found in Table 1.

Table 1. Matched Sample of MEPS Medicare Part D Beneficiaries (2006–2007) & CMS Claims Data

MEPS sample members reporting Medicare coverage	**7,293**
Exclusions	
Sample members with no identifiers for matching or did not match	4,479
Sample members with <12 months of Part D coverage or institutionalized for any part of the year	1,515
Sample members who used Veterans Administration or other federal pharmacies	28
Final number of matched sample members	1,271

Since our matched sample was not random, we adjusted the MEPS standard sampling weights to reflect the Medicare population. A logistic regression found that MEPS Medicare beneficiaries that matched to Centers for Medicare and Medicaid Services (CMS) data were more likely to be the household respondent, report their race as White compared with non-White, have completed high school, and have at least one prevalent, chronic condition compared with the Medicare beneficiaries who did not match exactly or who did not provide their HICN or SSN for the matching. We used a propensity-score reweighting procedure based on this regression to adjust the standard MEPS weights for differences in sociodemographic and interview characteristics in the likelihood of matching to CMS enrollment files. Applying the adjusted weight, we found no statistically significant differences in expenditures, and differences in survey-reported drug use between the matched and unmatched samples diminished but were not eliminated. This adjusted weight was used for all analyses.

Measures of Medication Use

Our two dependent variables of interest from the matched data are the number of distinct drugs and the number of fills/refills (i.e., the number of times each drug was obtained during the year). Drugs are defined as active ingredients (e.g., atorvastatin, omeprazole, clopidogrel). So if a person obtains the brand name and

generic for the same active ingredient, we count that once. If the person obtains both the regular drug and the extended release version or different strengths, we count that once. To ensure comparability, we excluded some drugs from both the MEPS and claims data. These are drugs not covered under Part D (e.g., barbituates, over-the-counter drugs, nearly all vitamins and minerals), drugs purchased during inpatient stays (rarely covered under Part D), and insulin and syringes (in MEPS, such information is collected differently than for other pharmaceutical items).

Control Variables

We created the following sociodemographic variables from the MEPS. Age was categorized as under 65, 65–74, 75–84, and 85 and older. Binary indicators represent the following categories: female, non-White, Hispanic, married, and living in an MSA. Region was categorized as North, South, Midwest, and West. Family income was coded as below 100, 100–199, and 200% or more of the federal poverty line (FPL). Education was categorized as <12, 12, and >12 years. There are five categories of perceived health: excellent, very good, good, fair, and poor. Binary indicators represented one, two, or three or more prevalent, chronic conditions (active asthma, diabetes, emphysema, high blood pressure, high cholesterol, ischemic heart disease, stroke, and arthritis or joint pain). A cognitive limitation indicator was coded "1" for persons who experienced confusion or memory loss, had problems making decisions, or required supervision for their own safety. An activity limitation indicator was coded "1" if the person received help or supervision with any activities of daily living (ADLs) or instrumental activities of daily living (IADLs) "because of impairment or physical or mental health problem." Medicaid was coded "1" if the person had Medicaid coverage any time during the year. Private drug coverage any time during the year was divided into coverage through an employer or union or other private coverage. We also constructed indicators describing the interviews and how utilization data were obtained for each beneficiary. Interview language was classified as entirely in English or at least one MEPS interview was in a language other than English. We classified reporting of drug use data into one of three categories: self-reported indicates that the sample beneficiary was the household informant in her last interview, household proxy indicates that use data were reported by a proxy living in the household, and nonresident proxy indicates that a person outside of the household reported use data for the sampled person. Finally, we created an indicator for year in survey.

Analytic Approach

We used both a descriptive approach and a modeling approach to assess the validity of the MEPS data. First, as part of the descriptive analysis, we examined weighted distributions of number of drugs and number of fills from each data source. We calculated Lin's concordance correlation coefficient to assess the agreement in measures between MEPS and the claims data. This coefficient contains measurement of both precision and accuracy and is used to assess the agreement between continuous variables. The correlation coefficient ranges from –1.0 (perfect disagreement) to 1.0 (perfect agreement) (Lin, 1989).

Second, we utilized negative binomial regression models to evaluate any potential differences in the predictive effects of the above-mentioned control variables. The regression analysis involved fitting two models for each dependent variable: one where the dependent variable is based on the MEPS data and one where the dependent variable is based on the claims data. Using the same set of explanatory variables (i.e., control variables) in each model, we calculated the marginal effect for each explanatory variable. We formally tested whether the effect of each covariate was the same in the pairs of regressions. For example, does poor health increase the number of drugs by the same magnitude whether using the household-reported or claims-based measure? Because coefficient estimates and the marginal effects are interpretable

as random variables, the comparison of marginal effects was analogous to a pairwise *t*-test of the means of two (correlated) random variables.

All analyses used the adjusted MEPS sampling weights to compensate for differences between the matched and unmatched samples and accounted for the stratified and clustered (at the PSU level) design of the MEPS survey.

Table 2. Comparison of MEPS Household Reported Annual Drug Use & Medicare Part D Claims Records, Matched Sample (2006–2007)

	MEAN (SE)				Ratio of		Agreement	Lin's
	MEPS		Claims		Means (SE)	κ-statistic	Rate (SE)	Concordance
Indicator of any drugs (0/1)	0.95	(0.01)	0.95	(0.01)	1.00 (0.01)	0.66	0.97 (0.01)	
Number of drugs	6.52	(0.20)	8.49	(0.28)***	0.77 (0.01)			0.71
Number of fills	37.40	(1.60)	38.2	(1.60)	0.98 (0.02)			0.81

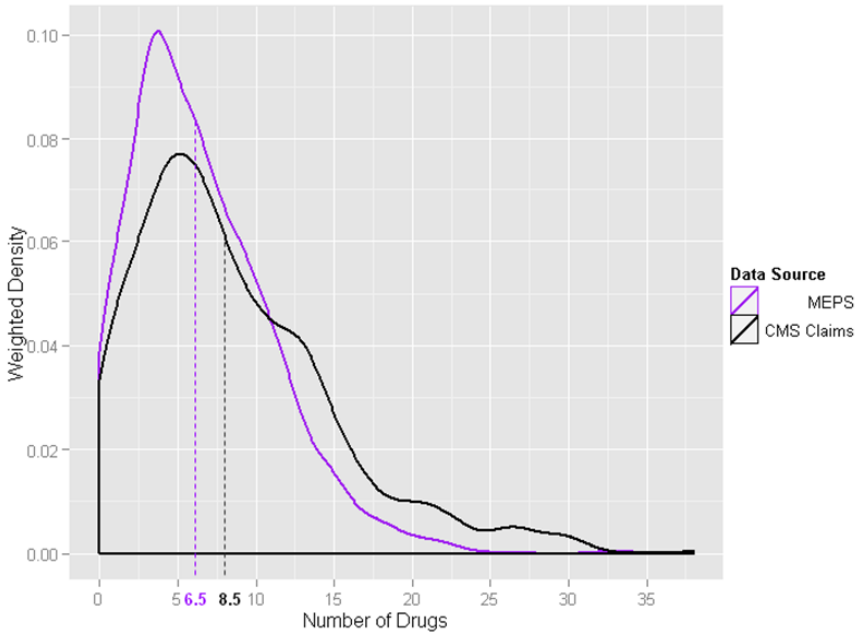
N = 1,271.
NOTE: All estimates were weighted using the propensity score-derived weight for the matched sample.
SE = standard error.
*** *p*-value < 0.01 for difference between MEPS and claims measures of utilization.

RESULTS

Descriptive Analyses

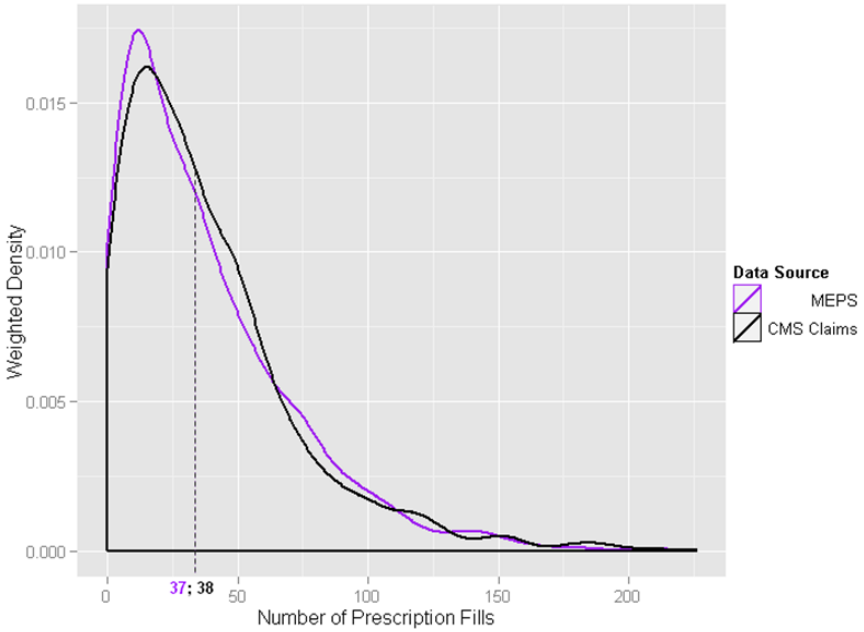
Table 2 compares mean utilization based on claims and MEPS household reports for our matched sample. There were no differences in the proportion of beneficiaries reporting any prescription drug use, with an agreement rate of 0.97 (95% CI: 0.96–0.98) and a κ statistic of 0.66, indicating "substantial" agreement (Landis & Koch, 1977).

Figure 1. Density Distributions for Number of Drugs, by Data Source, MEPS Matched Sample (2006–2007)



N = 1,271. Dashed lines represent mean numbers of drugs.

Figure 2. Density Distributions for Number of Fills/Refills, by Data Source, MEPS Matched Sample (2006–2007)



N = 1,271. Dashed lines represent mean numbers of fills or refills.

Figures 1 and 2 show the overlaid density distributions (MEPS/claims) for number of drugs and number of prescription fills, respectively (the dashed lines represent means). On average, MEPS respondents tended to report fewer drugs compared to what is documented in the claims data: 6.5 vs. 8.5. This is illustrated in Figure 1 with the higher peak in the MEPS distribution compared to the claims distribution. As measured by Lin's statistic, overall concordance between the MEPS and claims number of drugs at the person level was good: 0.71 on a scale from –1.0 to 1.0, but respondents in MEPS did tend to underreport their number of medications (Table 2). Further analyses suggest that the observed underreporting in MEPS is for short-term medications (e.g., antibiotics, topical agents, pain medications).

The density distributions in Figure 2 are much more similar. Table 2 shows there is greater concordance for number of fills or refills than for number of drugs. The mean number of fills reported in the MEPS was 37.4, compared with 38.2 in the claims for the analytic matched sample. As measured by Lin's statistic, overall concordance between the MEPS-reported and claims number of drugs at the person-year level was very good: 0.81.

Differences in reporting vary with some drug use patterns and sociodemographic and interview characteristics, and some of these factors differ across medication use measures. All sociodemographic groups underreported the number of drugs obtained (data not shown). On average, married beneficiaries, those residing in the West, those with higher incomes, and those not in Medicaid reported more of the drugs found in the claims data. Similarly, concordance for number of drugs was higher for sample members who were age 65–74, had higher incomes, and had better health. Part D beneficiaries who reported their drug coverage was through an employer also were less accurate in reporting the number of drugs. Some patterns of drug use were associated with better reporting of the number of drugs. The number of drugs was more accurately reported for sample members who reported receiving free samples and those who used fewer drugs. In fact, beneficiaries who obtained fewer than six drugs had the highest ratio of reported drugs to claims drugs. Also, interview characteristics were associated with better reporting: conducting the interview in English and using bottles and receipts to enumerate the medications obtained.

For most sociodemographic characteristics, the number of reported fills was similar to the number of claims (data not shown). Reporting patterns varied across the age distribution. People below the poverty line and those enrolled in Medicaid tended to underreport, but those with higher incomes and not in Medicaid did not. Those with fewer drugs and fewer fills in the claims were more likely to overreport fills. This could be a floor effect: when few fills are reported, it is harder to underreport them. Those with 16 or more drugs or 41 or more fills were more likely to underreport fills. The number of fills was more accurately reported for interviews conducted in English and when bottles and receipts were used to enumerate the medications obtained.

Regression Analyses

Some of the sociodemographic factors associated with better reporting are clearly related to each other (e.g., health status and number of chronic conditions). So, rather than using multivariate regressions to estimate their independent effects on reporting accuracy, we focused on the impact of reporting error in typical behavioral analyses of health care use.

Table 3 reports the results of pairs of regressions of the determinants of prescription drug use based on MEPS household-reported measures and claims measures, respectively, as the dependent variable and the same set of covariates from the matched sample. The first set of columns shows the marginal effects from the number of drugs regressions. There were marked gradients in perceived health status and number of chronic conditions, with no statistically significant differences between the marginal effects. Women and beneficiaries with ADL/IADL limitations obtained more drugs, and the magnitudes and statistical significance were similar across regressions. The differences were mainly in insurance status. The effect of Medicaid coverage was larger for the claims-based number of drugs (1.90) than the MEPS number of drugs (1.05, $p = 0.030$). The MEPS-claims difference was larger for the effect of reported employment-related insurance on number of drugs (0.40 versus 1.72, $p = 0.035$). Using the claims data, Hispanics were associated with 0.01 fewer drugs, but using the MEPS measures, the effect was 1.00 drugs ($p = 0.083$). The magnitude of the effect of residing in an urban area was similar across the pair of results, but the MEPS estimate was marginally significant, whereas the claims-based estimate was not. The effects of income were small and statistically insignificant in both models, but the signs were reversed and the differences were statistically significant at the 10% level. The marginal effects were small and not statistically significant in any regressions for age, race, marital status, having a high school education, having a cognitive limitation, reporting private drug coverage not through an employer, and residing in the Midwest, South, or an MSA.

The second set of columns in Table 3 shows the marginal effects from the number of fills or refills regressions. Perceived health status, number of chronic conditions, ADL/IADL limitations, women, residing outside an MSA, and Medicaid coverage were associated with more use in both sets of marginal effects. For these variables, the marginal effects were similar and have similar levels of significance. The magnitude of the effect of residing in the West was similar across the pair of results, but the claims-based estimate was marginally significant, whereas the MEPS estimate was not. The marginal effects of non-English language interviews were imprecisely estimated in both regressions, but the difference was statistically significant (3.7 vs. 11.1, $p = 0.049$). The effects of income were small and statistically insignificant in both models, but the signs were reversed and the differences were statistically significant. For example, in the MEPS, income more than twice the poverty line was associated with 2.9 additional fills, compared with 2.2 fewer fills in the claims data ($p = 0.015$).

CONCLUSIONS

Our comparisons of household-reported prescription drug use to Medicare Part D claims in the matched analytic sample revealed that household respondents in the MEPS were consistent with claims when reporting the number of fills and refills but underreported the number of drugs. Consistent with other validation studies of reported drug use, we found that the drugs that were not reported typically have short-term or intermittent uses (anti-infectives, topical agents, and pain medications), rather than maintenance drugs.

MEPS respondents typically report on drug use over a five-month period, so drugs that were used early in the reference period could be forgotten at the time of the interview. Generally, marginal effects from drug use and expenditure regressions have the same sign and often similar magnitudes.

Table 3. Comparison of MEPS & Claims-Based Drug Use Regression Model Results, Matched Sample (2006-2007)

	NUMBER OF DRUGS					NUMBER OF FILLS OR REFILLS				
CHARACTERISTIC	MEPS Marginal Effect	(SE)	Part D Claims Marginal Effect	(SE)	Difference (*p*-value)	MEPS Marginal Effect	(SE)	Part D Claims Marginal Effect	(SE)	Difference (*p*-value)
Age										
65–74	−0.40	0.44	−1.08	0.72	0.183	−1.9	3.4	−3.9	3.9	0.516
75–84	−0.44	0.46	−0.40	0.71	0.921	−5.2	3.2	−2.8	3.7	0.417
85+	−0.64	0.64	−0.79	0.96	0.834	4.3	5.6	2.0	5.8	0.581
Nonwhite	−0.16	0.33	0.01	0.56	0.680	−3.7	2.7	−3.8	2.6	0.939
Hispanic	−1.00*	0.58	−0.01	0.85	0.083	−4.9	4.4	−5.3	4.4	0.865
Women	1.23***	0.31	1.53***	0.39	0.264	6.7***	2.3	5.8**	2.3	0.602
Married	−0.14	0.36	−0.58	0.48	0.151	0.5	2.8	−0.1	2.8	0.748
Region										
Midwest	0.31	0.54	0.60	0.69	0.523	4.7	4.7	4.1	4.8	0.757
South	−0.13	0.46	−0.48	0.67	0.419	−0.9	4.3	−2.3	4.5	0.540
West	−0.12	0.52	−1.07	0.68	0.013	−6.2	4.2	−7.8*	4.3	0.415
MSA	−0.72*	0.40	−0.72	0.51	0.993	−9.2***	3.5	−7.2**	3.1	0.297
Family Income										
1–2× FPL	0.28	0.37	−0.32	0.50	0.078	4.4	2.8	−1.3	3.0	0.003
>2× FPL	0.44	0.42	−0.24	0.60	0.057	2.9	3.2	−2.2	3.5	0.015
Education (years)										
12	0.13	0.32	0.20	0.50	0.855	−1.5	2.6	−0.2	2.7	0.477
>12	1.00**	0.42	1.35**	0.62	0.394	1.9	3.4	1.1	3.1	0.737
Perceived Health										
Very good	1.41***	0.40	1.48**	0.63	0.979	11.0***	3.0	11.0***	2.8	0.598
Good	2.53***	0.44	2.55***	0.71	0.937	19.6***	3.4	18.1***	3.3	0.223
Fair	3.49***	0.49	4.15***	0.71	0.401	24.4***	3.1	21.8***	3.1	0.141
Poor	5.09***	0.64	5.69***	0.93	0.453	40.4***	5.7	30.7***	5.1	0.011
Chronic Conditions										
1	1.51***	0.40	2.91***	0.61	0.004	8.8***	2.4	10.8***	2.4	0.602
2	3.22***	0.40	3.97***	0.55	0.053	19.6***	2.6	20.0***	2.9	0.951
≥3	5.50***	0.39	7.09***	0.49	0.001	35.5***	2.6	34.8***	2.4	0.764
Cognitive Limitation	0.38	0.36	0.13	0.57	0.546	−0.7	3.0	−1.3	3.1	0.773
ADL/IADL Limitation	1.05**	0.42	1.31**	0.52	0.397	7.5**	3.1	9.5***	3.2	0.322
Insurance										
Medicaid	1.05**	0.42	1.90***	0.61	0.030	9.4***	3.4	13.1***	3.8	0.125
Employment-related	0.40	0.55	1.72**	0.87	0.035	−0.3	4.2	3.9	4.2	0.200
Other private	0.22	0.60	−0.01	0.68	0.519	−4.5	3.5	−3.2	3.0	0.548
Non-English Interview	0.99	0.75	2.16*	1.21	0.156	3.7	5.9	11.1	7.3	0.049

N = 1,271.

NOTES: Marginal effects from negative binomial regression models. All estimates were weighted using the propensity score-derived weight for the matched sample.

*$p < 0.10$, **$p < 0.05$, ***$p < 0.01$ for marginal effects.

ADL = activities of daily living; FPL = Federal poverty line; IADL = instrumental activities of daily living; MSA = metropolitan statistical area; SE = standard error.

We note two potential limitations in our comparisons of MEPS household reporting to Medicare claims. First, we matched a large sample of Medicare beneficiaries in MEPS to claims data, but our matched sample itself was not nationally representative of Medicare beneficiaries. However, we note that our matched

sample mirrors expenditures by the full sample of Medicare beneficiaries in MEPS when using weights adjusted for differential matching. Second, we examined household reporting for Medicare beneficiaries only, and our findings may not generalize to the reporting for other family members of Medicare beneficiaries or to the rest of the U.S. population residing in households with no Medicare beneficiaries. Elderly and disabled Medicare beneficiaries use substantially more health care services than other Americans (Ezzati-Rice, Kashihara, & Machlin, 2004), and a previous study and results presented here suggest underreporting is greatest among higher use groups (Poisal, 2003–2004). To this extent, our findings may provide an upper-bound estimate of underreporting for the full MEPS sample. The elderly and disabled Medicare populations differ in other important ways from the rest of the population, but it is unclear how this would affect reporting of prescription drug use.

On average, MEPS estimates of the number of fills and inpatient use are similarly close to claims-based estimates. The accuracy of medication use in the MEPS compares favorably with the accuracy of medication use in other surveys. In the MEPS, the number of fills is underreported by 2%, on average, compared with 17% in the MCBS (Poisal, 2003–2004). In the MEPS, we found households reported very few medications not found in the claims data. While Poisal found considerably more overreported fills in the MCBS (23% of beneficiaries overreported), the problem could be due to missing pharmacy data, whereas our study compares the MEPS with claims data. Like the MCBS, underreporting in the MEPS is higher among beneficiaries who obtained more fills and refills. While the MCBS and MEPS are similar surveys, the results may not be fully comparable, because we studied beneficiaries in the Part D program, whereas Poisal studied all Medicare beneficiaries before Part D began. After Part D began, the MCBS used the Part D claims rather than household reports to measure use and expenditures covered by Medicare and survey reports for use covered by other payers.[2] Like Van den Brandt et al. (1991), we found accuracy decreases with the number of drugs used. Like Caskie and Willis (2004) and Caskie et al. (2006), we found cognitive ability does not affect reporting, but the household respondent likely reports for the more severely impaired sampled persons. We also found, like Caskie and Willis, that accuracy increases with income.

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The RWJF Health Care Public Perceptions Index: Index Development, Results, and Support for Reform

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INTRODUCTION

The health care system is undergoing a major change in how insurance is delivered in the U.S. with the passage of the Patient Protection and Affordable Care Act (PPACA). Most of these reforms have yet to be implemented, and understanding the effects is critical to both successful policy and additional reforms. In light of these changes, we developed an index to measure consumers' confidence in their health-related experiences and their expectation for the future. Released in April 2009, the index is designed to track changes in public perceptions of health care during the process of health care reform and implementation of the PPACA. The goals of this paper are to (1) describe the development of the index and its validity, (2) describe demographic differences in index levels, and (3) show how the index related to support for reform prior to PPACA's passage.

The health care system affects individuals in many ways, including their sense of security. Assessing these perceptions in their day-to-day lives provides a basic measure of the system's performance. As opposed to a narrow program with well-defined metrics for evaluation, the PPACA health reform law presents a broad set of changes in the system. The Robert Wood Johnson Foundation (RWJF) Health Care Public Perceptions Index provides an opportunity to capture the impacts of many policies and provides a bellwether measure of the impacts on confidence.

Disparities across the population in access to health care are well documented. These have translated into varying levels of support for reform. In 2010, support for health care reform was higher among women, younger Americans compared to those older than 65, non-Whites compared to Whites, and those with lower incomes (Blendon & Benson, 2010). Furthermore, research has suggested that members of the public who have the most to gain from changes to the health care system, and thus are more self-interested in the policy, tend to support reform more than others. For example, people who are more confident that they can pay for their own medical care express more support for government responsibility for health care (Jacobs & Shapiro, 2000); people lacking health insurance support government insurance more than those who do not (Koch, 1998); and people who are disabled, cannot afford health insurance, or have lower incomes are also more likely to support government-provided health insurance (Lau & Heldman, 2009). Even research that has sought to demonstrate the relatively low predictive power of self-interest on public policy attitudes has found that when it comes to health insurance policy, those with more need for health insurance are more likely to support changes to the health care system (Sears, Lau, Tyler, & Allen, 1980).

INDEX METHODOLOGY

Survey Information

The core survey sample is designed to be representative of all households in the coterminous United States. The core of the Surveys of Consumers questionnaire is composed of 50 questions designed to track different aspects of consumer attitudes and expectations. Added to this was the Health Care Security supplement, which consisted of 23 questions. The monthly response rate is approximately 39% (using the

AAPOR Response Rate 2 calculation). The margin of error for the survey is 4.4% at a 95% level of confidence.

Factor Analysis

Index development included a principal components factor analysis to isolate the items providing the most efficient measure of the two targeted constructs: recent experiences and future expectations. A list of 18 items, field-tested for relevance, generated two factors with eigenvalues greater than one, among nine items. These items correlated exactly with the questions phrased to include recent experiences and future expectations. Cronbach's alpha from the inter-item correlations is midranged at 0.85 for each construct and the combined construct.

Item Validation

Individual items from the index are found in a variety of existing surveys. The National Health Interview Survey (NHIS) has estimated the percent who have delayed care or skipped treatment due to cost at 10.9% and 8.0%, respectively. These items have remained relatively stable from year to year, peaking in 2003 at 11.3% and 9.0%, respectively. In our survey, the rates are higher at 21% and 20%, respectively. The increase is likely due to the household phrasing of the question, which asks if the respondent or anyone in the family has delayed care. Shown in Table 1 are the levels from the RWJF survey for items used in the index compared with the Kaiser Health Tracking poll for March 2010 (the approximate midpoint of the survey). The Kaiser poll tends to run about 10 points higher for each of the items. A context effect is suspected because the Kaiser poll centers on problems and issues in health care whereas the Surveys of Consumers is more positively oriented around confidence.

Table 1. Item Validation

#	Item	RWJF (24-month average)	Kaiser (March, 2011)
1	Delayed seeing a doctor due to cost	21	30
2	Skipped treatment due to cost	20	28
3	Skipped prescription due to cost	19	26
4	Difficulty paying medical bills	23	30
5	Worried about losing coverage	25	48
6	Worried cannot afford serious care	49	57*
7	Worried cannot afford routine care	44	57*
8	Worried cannot afford drugs	42	52
9	Worried about bankruptcy from medical bills	27	NA

* "Not being able to afford the health care services you think you need*
NA = Not available.

Index Construction

Similar to the economic index in the Surveys of Consumer Sentiment, the health index is composed of recent and future subindices. To calculate the indices for each person, each of the nine items in the index is given a score of 0 if negative, 1 if neutral, and 2 if positive.

The Recent Health Cost Barriers (RHCB) Index is constructed first by summing the item scores for each person by month. Then, the base period is established by summing the total scores for the first two months of the survey and dividing by the number of respondents in the period. The published index is calculated by dividing the monthly score by the base period score. The scores and respondent counts are weighted.

Similar to the RCHB Index, the Future Health Cost Concerns (FHCC) Index is constructed first by summing the item scores for each person by month. However, because item 5 is only for the insured, the weights for the other four items are increased proportionately. The base period is established by summing the total scores for the first two months of the survey and dividing by the number of respondents in the period. The index for each person is calculated by dividing the monthly score by the base period score. The RWJF Index is simply the average of the two subindices. Alternatively, it can be calculated independently using all nine items.

Index Validation

The results of the factor analysis suggest the index is capturing the concepts of recent experiences and expectations underlying the various items in the survey. Another way to look at the performance of the RWJF index is to compare it with other indices measuring similar concepts. The Consumer Healthcare Sentiment Index (CHS; Pickens, 2011) is calculated from the items asked of 3,000 households per month using a methodology nearly identical to the one developed for the RWJF Index. An early version of the index began in March 2009, and a revamped version established its baseline in November and December 2009. Month-to-month movements in the index are very similar to the CHS Index. A de-meaned regression model of the two indices gives an adjusted R-square of over 52%, suggesting that although the RWJF Index moves up and down from month to month, the movement is more likely related to actual oscillations in perceptions than random noise. Additional tests of validation should be undertaken as more data become available.

ANALYSIS METHODOLOGY

Demographic Patterns

The demographic patterns in the data were assessed by calculating the mean index values for each subpopulation and testing their difference from the overall total. The percentage difference is discussed to provide a relative measure of the disparity. Data for the analysis is drawn from the survey sample between April 2009 through the end of April 2010. This provides for 6,633 total observations.

Support for Reform

As described in the introduction, research about the relationship between public perceptions and policy suggests that individuals who are less confident in their access to care have more to gain by policies expanding coverage. To test this hypothesis, we looked at a another question on the survey that asks "How important is it that President Obama include health care reform as part of his approach to addressing the economic crisis of the United States?" This question is a bit problematic because it combines the concepts of support for reform with how to approach the economic crisis; however, the responses are thought to be driven by an individual's support for reform. The percentage of those who answered "very important" or "somewhat important" were categorized by their overall index score. The differences in the percentages were tested using *t*-tests of proportions. Additionally, we report the percentage who thought reform would make their own finances and access better as well as the percentage who thought it would make the country's finances and access better. The question was fielded continuously between April 2009 and March 2010.

RESULTS

Demographic Patterns

As Table 2 indicates, those age 65 or older had a higher level of confidence than each of the other age groups (18–34, 35–49, 50–64). Given the high rate of insurance, this is not unexpected. However, it is somewhat surprising given that their health status was the lowest on average and lower health status is associated with lower levels of confidence. Those in the 50–64 age group were significantly more confident than the 18–34 year old age group for the recent index, but the reverse was true for the future index. Lower overall confidence was found among minority racial/ethnic groups (17% lower for Hispanics and 8% lower for Blacks), among the lowest third of income (16% lower), among lower education levels (9% lower for high school or less), among females (4% lower), among those with lower health status (23% lower for fair/poor), and among the insured (41% lower).

Table 2. Respondent Demographics

CHARACTERISTIC	Population (%)	Recent Mean	Future Mean	Overall Mean	*N*
OVERALL	100.0	101.4	97.3	99.4	6,633
Age					
18–34	16.3	93.6	100.7	97.2	765
35–49	27.9	96.3	96.7	96.5	1,684
50–64	30.3	98.5	90.4	94.4	2,203
65+	25.5	115.5	104.0	109.7	1,981
Race					
White non-Hispanic	81.7	103.1	100.4	101.7	5,414
Black non-Hispanic	8.5	92.8	90.7	91.8	539
Hispanic	6.5	93.4	72.3	82.8	355
Other	3.4	100.8	86.5	93.6	196
Income					
Bottom third	31.9	89.4	76.5	82.9	1,791
Middle third	34.0	99.0	95.5	97.3	2,151
Top third	34.2	113.5	118.1	115.8	2,181
Education					
HS or less	33.0	97.8	83.0	90.4	2,076
Some college	23.2	96.3	93.8	95.0	1,504
College degree	25.8	104.9	107.3	106.1	1,724
Grad studies	18.0	109.3	113.8	111.6	1,315
Sex					
Male	44.4	104.8	103.7	104.3	2,846
Female	55.6	98.7	92.2	95.4	3,787
Health Status					
Excellent	18.3	115.1	120.2	117.7	1,233
Very good	30.8	109.1	109.5	109.3	2,040
Good	28.8	99.3	90.3	94.8	1,930
Fair/Poor	22.1	82.7	70.8	76.7	1,411
Insurance Status					
Insured	89.7	105.5	102.7	104.1	6,065
Private insurance	77.0	107.2	105.6	106.4	5,262
Public insurance	40.1	107.2	98.2	102.7	2,578
Uninsured	10.3	65.8	50.9	58.3	554

Support for Reform

Overall, the support for reform was at 80% during the sample period. As shown in the Table 3, the percentage supporting reform was higher for those with a low overall index score. These results suggest that the policies in the reform were targeted at those lacking access. Similarly, a higher percentage of people with lower confidence responded that it was likely to improve their own finances and access. When asked about how the reform would affect the country's finances and access, the results did not display a similar trend. This suggests that the trend is not just a function of having low confidence in the future.

Table 3. Importance of Health Reform

		Impact on Self		Impact on Country	
FHCCI index	Reform Important	Access Better	Finance Better	Access Better	Finance Better
0	92%	28%	26%	40%	33%
1–32	84%	17%	16%	31%	26%
33–75	83%	16%	14%	34%	26%
76–125	81%	18%	16%	38%	33%
126–157	75%	10%	6%	39%	32%
158	76%	8%	7%	39%	33%
TOTAL	**80%**	**14%**	**13%**	**38%**	**31%**

DISCUSSION

PPACA presents many changes to the health care system that may affect health confidence in many ways. Given the difficulty of knowing what issues may arise once health reform is implemented, a broad measure of the system, rather than individual features that may be irrelevant after reform, may be desirable. The RWJF indices provide a valuable opportunity to evaluate a broad-based measure of the effects of health reform. The index itself, however, primarily covers items related to access and cost. Therefore, changes in the system that do not pertain to these will be missed. Concerns about choice of plans and potential interference in the doctor-patient decision are examples of topics that may be affected by reform but may not show up in the items of the index. The index is scheduled for suspension in April of 2011. Nonetheless, with two years of consistent monitoring, it is well poised to be re-instituted once implementation of PPACA is further along. Also, due to the similarity with the Thomson Reuters Healthcare Sentiment Index, it may be possible to use the results from that index as a proxy for months missing in the RWJF Index.

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APPENDIX. ITEM WORDING

J1: In the past 12 months, was there any time when you (or someone in your family living there) delayed seeing a doctor when it was necessary because of the cost? (Yes/No/Don't know)

J2: In the past 12 months, was there any time when you (or someone in your family living there) skipped a recommended medical test, treatment, or follow-up because of the cost? (Yes/No/Don't know)

J3: In the past 12 months, was there any time when you (or someone in your family living there) did not fill a prescription because of the cost? (Yes/No/Don't know)

J4: In the past 12 months, did you (and your family living there) ever have difficulty paying for your medical bills? (Yes/No/Don't know)

J5: [If insured] At this time, how worried are you that you will lose your health insurance coverage in the next 12 months? Are you very worried, somewhat worried, not too worried, or not worried at all?

J6: Thinking about the future, how worried are you that you will not be able to afford treatment if you (or someone in your family living there) become(s) seriously ill? (Are you very worried, somewhat worried, not too worried, or not worried at all?)

J7: Thinking about the future, how worried are you that you will not be able to afford all of the routine health care services you (and your family living there) might need? (Are you very worried, somewhat worried, not too worried, or not worried at all?)

J8: Thinking about the future, how worried are you that you will not be able to afford all of the prescription drugs you (and your family living there) might need? (Are you very worried, somewhat worried, not too worried, or not worried at all?)

J9: Thinking about the future, how worried are you that you will go bankrupt from not being able to pay your (family's) medical bills? (Are you very worried, somewhat worried, not too worried, or not worried at all?)

SESSION 2 DISCUSSION

Joel W. Cohen (Division of Social and Economic Research,
Center for Financing, Access and Cost Trends, Agency for Healthcare Research and Quality)

The papers in this session cover many of the critical issues health care reform is designed to address. The main goal of the recent Affordable Care Act (ACA) is to provide insurance coverage to many more Americans, and the mechanism is expansion of both public and private insurance. In addition, with health care costs accounting for more than 18% of the Gross Domestic Product and continuing to rise faster than other sectors of the economy, the issue of how to encourage the most efficient provision of care and contain costs without harming quality of care are vitally important. Finally, as we have seen in the debate of the health care reform bill, public perceptions of the health care system and potential changes to it can shape the political landscape in the country, which in turn has substantial impacts on whether and how policies are implemented.

Survey data have a vital role in informing policy makers and the public about the parameters of the current system and what the effects of specific changes to that system would be. For example, in addition to basic descriptive and behavioral analyses, survey data are at the core of every major microsimulation model used by policymakers to evaluate proposals for change. Survey data also have a number of advantages over administrative data in monitoring and analyzing the U.S. health care system. While administrative data are designed for specific purposes and can be used effectively in some types of analyses, they typically are drawn from selected populations, are not flexible with respect to tailoring or changing the information collected, and tend to be very difficult to access. In contrast, surveys provide generalizable data, can be tailored to specific purposes, and typically are widely disseminated.

As background for my comments, I would like to start with a few personal principles I have found helpful in guiding my work on survey design and data analysis over the last two decades. I think they are relevant to the papers in this session and are useful to keep in mind when engaged in collecting and analyzing survey data, particularly in terms of maintaining realistic expectations as to what can be done in surveys. These principles are as follows:

1. Nothing is simple in the U.S. health care system,
2. Insurance coverage is harder to measure than you think,
3. Obtain estimates of ostensibly the same thing from two different sources, and you'll get two different estimates, and
4. Respondents don't know what they don't know.

For the most part, these points are self-evident, but my experience has been that it is easy to forget them when engaged in the pursuit of some important policy-relevant piece of information. For example, an analyst might want to do a survey to find the answer to what seems to be a fairly simple question—say, how many people are uninsured. Points one and two are relevant here. First, although it may seem on the surface relatively straightforward to tell whether someone is insured, in the U.S. system there are a number of gray areas. For example, if an individual is eligible for care for a service-connected illness through the Department of Veterans Affairs or for care at an Indian Health Service facility, is that the same as having private insurance or Medicare, which provide broad coverage of illnesses and sites of care? How exactly is insurance coverage defined, and how do you operationalize that definition in a household survey? Second, distinguishing between different types of insurance, which is critical for policy purposes, can be very difficult in a survey. For example, research has shown that many Medicaid beneficiaries think they are

covered by nongroup private insurance, even though the alleged private insurance is really Medicaid coverage purchased through a private insurer by the state. Given that, how does one distinguish between private and public coverage in a household survey? Insurance coverage is a good example of point three as well. Different national surveys produce very different estimates of the number of uninsured people in the U.S. Some of this is due to differences in samples, reference periods, and scope, but the differences exist even for surveys in which the populations covered and definitions of coverage and insurance are ostensibly comparable.

Finally, the 4th point refers both to the fact that respondents often just can't answer a question accurately—for example, how much did your employer pay for your health insurance?—and to situations in which they think they are answering correctly but are unaware they are not. For example, in reporting how much was paid in total for their doctor visits, respondents often will subtract their out-of-pocket payments from the total charge appearing on a bill and tell you that insurance paid the rest, not aware that the insurer has negotiated a discounted fee with the provider. Government subsidies for insurance are particularly likely to be susceptible to this lack of awareness problem, which brings us to the specific papers presented in this session.

SELF-REPORTS OF PREMIUM ASSISTANCE (RUCINSKI)

This paper uses random samples from phone lists and administrative records to address the extent to which household respondents can report subsidies. The author finds that with a phone-based sample, government subsidies are less likely to be reported than private subsidies, and that even when using samples selected from lists of beneficiaries of government programs, less than half of respondents report receiving subsidies for their insurance coverage. The findings based on the beneficiary sample are particularly instructive, since selecting a sample from administrative records of who is signed up provides a "gold standard" for determining whether someone is covered. Unfortunately, no national gold standard for determining who receives public and private subsidies currently exists.

The findings from this study confirm that household respondents are not very good at reporting this kind of information. It is very difficult to get accurate information about insurance coverage from simple survey questions. Public coverage often gets mistaken for private coverage, because respondents think they are covered by, for example, Kaiser's private plan, but it is really Kaiser's Medicaid plan. Subsidies are particularly difficult to determine from household respondents because there are often transactions occurring behind the scenes about which respondents are not aware. In addition, it is very difficult to sort out Medicaid from Children's Health Insurance Plan (CHIP) coverage, since eligibility can depend entirely on an income cut-off, although the premium subsidy structures of the two programs are very different.

These issues are very likely to present a problem for monitoring changes produced by the ACA because employer and government subsidies implemented under the act can be very complicated. Interactions between employers, health insurance exchanges, and Medicaid/CHIP are likely to make determining the sources and amounts of subsidies extremely difficult for household survey respondents. The Health and Retirement Survey (HRS) approach has promise in at least determining how much of this information about which a respondent may be aware, but that will not necessarily lead to accurate responses about the amounts of subsidies. The additional questions needed to determine levels of awareness also could be prohibitive in terms of respondent burden.

IMPROVING THE AMERICAN COMMUNITY SURVEY (KENNEY & LYNCH)

This presentation examines the validity of insurance coverage estimates from the American Community Survey (ACS). The findings indicate that ACS insurance estimates are consistent with those from other national surveys for most types of coverage. The ACS does appear to have high estimates of the number of people with nongroup coverage and also has low estimates of the number of persons covered under Medicaid and CHIP. The authors propose some adjustments to the original nongroup and Medicaid/CHIP numbers based on logical edits that appear to improve those estimates, although even after the edits, the nongroup estimates still appear to be high and the Medicaid/CHIP estimates still somewhat low compared with administrative totals.

There are a number of features of the ACS that make it very useful for monitoring the effects of health reform. It is a very large survey, has very high response rates, and supports small area estimates; further, in general, the ACS-based estimates of insurance coverage look reasonable relative to other sources. Thus, the ACS is an excellent addition to the available data infrastructure on insurance coverage, even though it does risk adding to the concern about why estimates differ across surveys.

A main focus of this analysis is public coverage. Public coverage is an important issue in using survey data to evaluate the effects of reform because, as noted previously, reporting tends to be poor for Medicaid and CHIP beneficiaries. Comparisons between survey and administrative data consistently show that Medicaid coverage tends to be substantially underreported in surveys. Because the ACA addresses a large portion of the uninsured problem by expanding public coverage, accurate estimates of both public coverage and the uninsured are critical to evaluating the impact of reform. Adjustment strategies can help, but in using them, analysts have to be careful not to make asymmetric adjustments that introduce bias into the data. For example, adjustments such as switching some uninsured to public coverage but no publicly insured to uninsured can bias estimates and behavioral analyses. Also, changes in editing procedures can make trend analyses difficult, as it may be difficult to later disentangle a shift in the trend resulting from a change in policy from a shift due to a new edit. Of course, this is a problem faced by all ongoing surveys.

COMPARING COUNTS OF ED VISITS (RHOADES, COHEN, MACHLIN, & ROEMER)

This analysis compares counts of emergency department visits from the MEPS household survey with similar data from the MEPS provider survey to determine the extent and reasons for differences in total visits counts between MEPS and other sources of emergency department (ED) visit data. Historically, MEPS ED visit totals have been consistently lower than those produced by other surveys, although totals for overall ambulatory visits, including office-based and outpatient-based care, are very similar. MEPS, however, tends to show more office-based visits and fewer ED visits than the National Center for Health Statistics (NCHS) provider surveys, the National Ambulatory Medical Care Survey (NAMCS), and the National Hospital Ambulatory Medical Care Survey (NHAMCS), and those differences have been consistent over time. The reasons for the differences are not clear. Potential explanations include underreporting by household respondents, misclassification of sites of care by household respondents, and differences in the definition of what constitutes an ED visit from the household and provider perspectives.

This paper attempts to shed light on this issue by comparing household-derived reports of ED utilization with provider derived reports for all sampled persons in the2008 MEPS who had any hospital use reported in the household survey. The findings indicate that among those in the household survey for whom the respondent reported any ED visits, there was underreporting in the tail of the distribution—that

is, for individuals with a large number of visits during the year, only some of them were reported; there was also underreporting of any use. However, even accounting for both of these sources of underreporting, a gap between MEPS and other surveys in total ED visit counts remained. Thus, there is still an unexplained component, something besides underreporting, to the difference in estimates from MEPS compared with other surveys.

This analysis illustrates another good use of administrative data. Because the MEPS collects provider data for hospital events, as well as household reports, the household reported data on utilization can be compared with matched provider data. Using these comparisons, the authors were able to explain at least part of the difference in ED visits counts and, unsurprisingly, that part is a function of underreporting by household survey respondents. The remaining gap is more puzzling, however, and much harder to examine. This also points out some of the limitations of administrative data. The available matched data in the MEPS represents a selected sample, i.e., persons who reported hospital events in the household survey. That means the authors could not look at persons who did not report anything in the household survey but actually did have one or more ED visits. It is not clear how one could use administrative data to examine this issue. Also, the question of the extent of misclassification remains. Are household respondents reporting visits the hospital classifies as ED visits as either outpatient or office-based care? Further research is needed to sort this out. Finally, it would be helpful to extend the study to examine the effects of underreporting on behavioral analyses, as was done in the previous presentation on MEPS prescribed medication data.

ACCURACY OF MEPS PMED DATA (ZODET, HILL, & ZUVEKAS)

This paper looks at the accuracy of Medical Expenditure Panel Survey (MEPS) use and expenditure estimates for prescribed medications (PMEDS). The authors compare the MEPS estimates with Medicare Part D claims data for a matched sample of Medicare beneficiaries. They pay very careful attention to making the data as comparable as possible across the two data sources and generally find that MEPS estimates are consistent with use and expenses data derived directly from Medicare claims. They also find that what differences do exist do not have a substantial impact on behavioral analyses of PMED use and spending.

The paper demonstrates a very good use of matched survey and administrative data, which generally provides the best "gold standard" for evaluating the accuracy of surveys. Given the difficulty of pulling claims for particular survey respondents and ensuring the comparability of the types of claims examined, this paper does a good job of comparing survey estimates with actual claims. However, the small sample size and selected population are limitations of the analysis, as noted by the authors. There remains a question about whether the findings for this population are applicable to the privately insured. It would be useful to do the same analysis with private claims, but a comparable data set for use in conducting that analysis is not available. Nonetheless, the finding that any measurement errors in MEPS are unlikely to affect behavioral analyses for the Medicare Part D population does suggest that MEPS prescribed medication data are likely to be a good source for evaluating the effects of health care reform on PMED use and expenditures for other populations as well.

HEALTH CARE CONSUMER SENTIMENT INDEX (GRAVEN)

This paper describes the development of an index to track individuals' current perceptions and expectations for the future of the U.S. health care system to gauge how perceptions of that system change over time. The index was based on nine items from existing surveys that measured people's recent experiences with the affordability of care and their degree of concern with the cost of care in the future, and

produced separate index scores for recent problems, concern about the future, and a composite score. The authors then examined these scores in the context of the recent debate over health care reform legislation. They found a relationship between individual circumstances and people's opinion on reform, with a low score on the overall index—indicating more problems and concerns with the affordability of care—associated with greater support for reform of the system.

This paper represents a good use of existing survey questions to develop an index of individuals' perceptions of the health care system. There are a few areas of the analysis that could use some additional explanation, however. First, I had some questions about item validation. The table comparing the results from this index and the Kaiser Health Tracking poll for the same items in some cases showed substantial differences. In part this appeared to be a function of the questions being slightly different, but if small wording changes can produce large differences in results, what are the implications for the utility of the index? Another aspect of the study that could use some additional explanation is the multivariate analysis. It was not clear whether any additional variables, aside from the indices, were used in the analysis to control for other factors that might affect people's perceptions of health care in the U.S. It would be helpful to spell this out more clearly, as well as clearly stating the specific regression equation estimated.

The model specification issue leads us as well to what is perhaps the most important area of concern with the paper, which is the issue of attribution. Association does not necessarily imply causation. While the paper shows that changes in the index were associated with various health reform related events, I am a bit skeptical that the general public was following those events closely enough to be influenced by them. Did the events identified really affect people's perceptions, or were they both shaped by something else? It might be helpful to include some measure of individuals' knowledge of these types of events to shed some light on this question. I would be more convinced of a causal impact if there was a measurable effect associated with the knowledge, and even more so if the effect was greater for those who were more closely following the health care debate.

I also wondered about the level of support for reform estimated in the paper. My understanding of public opinion polls is that support has been fairly stable at about 50/50. What accounts for the high support level found in this survey? Finally, it would be helpful to give some examples of how the index might be used in informing health care policy. For example, if the future index could be used to predict public support for various proposals to change the current system, it would help inform policymakers about how to prioritize those proposals and how difficult it will be to secure their adoption.

CONCLUSION

This set of papers provides a broad overview of the value of survey data in characterizing critical aspects of the provision and perceptions of health care in the U.S., as well as some of the difficulties involved in the collection and interpretation of data from health care related surveys. Because of their demonstrated past and clear future value, survey data certainly will be vital in monitoring the impact of health care reform and to continuing to inform consumers, policymakers, and providers about the current and projected state of the U.S. health care system.

SESSION 2 SUMMARY

Karen Bogen (Mathematica) and **Patricia Gallagher** (University of Massachusetts-Boston)

The floor discussion was largely an expansion of issues raised by the session discussant, notably that nothing is simple in U.S. health care and respondents may not know what they don't know. The complexity of the measurement issues related to health care reform described below follow directly from the fact that the system itself is complex and continually evolving. There is measurement infrastructure in place that will allow answers to some of the research questions, but that system may not be agile enough to provide the requisite data in the way and time that it's needed.

ISSUES & CONCEPTS GERMANE TO HEALTH CARE REFORM MEASUREMENT ARE COMPLEX

Health care reform itself is complex, and there is a call for new measures before regulators, practitioners, and patients are in a position to fully understand all facets of the legislation. For example, it's critical to measure health insurance coverage because one of the fundamental goals of health care reform is universal coverage. Thus, we need to further develop and test measures to track movement towards or away from that goal. The papers presented in this session identified underreporting of coverage, as noted in the Rucinski paper, and the misreporting of coverage in the ACS, as reported in the Lynch and Kenney paper. Another example of a critical but complex measure is health insurance exchanges, a concept that is just emerging and whose presentation to the public is still unformed but may soon dictate the development of relevant survey items. State variations in implementation and associated data needs also will influence item creation and wording. Another key area for measurement is health care utilization. The Rhoades paper demonstrated the underestimates in MEPS of emergency department use. Likewise, the Hill paper discusses the underreporting of prescription drug use in the Medicare population.

Another issue that was raised in the floor discussion was approaches to improving data quality for health care reform measures. For example, some states, such as Massachusetts, will be better suited for testing questions on these topics because a number of the features of health care reform are being implemented there first. The Kenney paper uses post-data-collection logic to edit some data, but there was agreement that while data editing might be useful, developing better survey questions is the ultimate goal.

The increasing demand for high-quality data, not just at the federal level but for state and small area estimates as well, resounded in the floor discussion. A key theme was whether survey data collection is approaching an audit activity (a simple counting that would be better done with administrative data) and if we are asking too much of respondents in terms of both interview length and level of detail requested. Survey researchers cannot ask respondents to report information or details they simply do not know (and may never have known), such as specifics about their insurance-covered health care expenses. There were comments that some respondents learn to answer in a particular way to shorten their interview length by avoiding the follow-up questions they have learned to anticipate. This is a long-known problem, and there was a suggestion to consider random reinforcement to minimize training respondents that way.

THE TOOLS FOR SUPPORTING THE MEASUREMENT OF THE IMPACT OF HEALTH CARE REFORM HOLD PROMISE BUT ARE NOT YET IDEAL

The tools currently in place and being used for measurement of health care include the ACS, MEPS, NHANES, and other federal data collection efforts. The ACS is large and more timely than the decennial census but doesn't provide estimates at state and local levels that will be required. Conference attendees discussed the challenges of expanding these large surveys in a timely manner to address emerging issues in health care reform. For example, the process of adding items to the ACS involves extensive discussion and negotiation with the Census Bureau and could take a number of years. Pressure from data users may cause the Census Bureau to respond more quickly to the data demands.

MEPS holds promise for collecting data about health care utilization and costs, but there are some questions around data quality, as noted above. The benefits and shortcomings of other federal data collection efforts also were discussed in other conference sessions.

The decidedly gray areas that exist in important health care concepts represent another major limitation of current surveys. For example, the floor discussion included the description of a free-standing urgent care center that looked very much like a doctor's office but that billed as an emergency department because it was affiliated with a nearby hospital. Would a respondent be able to correctly report that he/she was seen at an ED, or would this be identified as an office visit? An approach to tackling other gray areas might be to look at patient experiences and perceptions in the manner described in the Graven paper, where respondents are asked to report both about recent experiences and future concerns. This approach bypasses difficult health care reform concepts themselves and looks at recent experiences and distal outcomes that can be tracked over time, such as delaying care due to costs.

Floor discussion emerged about how much we should rely on self-reports versus electronic health data. Health industry consolidation is bringing together administrative data sources as well as giving researchers the opportunity to collaborate and build relationships with industry and government, the owners of the electronic health records and administrative data. Others pointed out that survey data provide a richer and deeper source of information on sociobehavioral domains such as expenditures and demographics. There was a call for combining survey and administrative data to optimize data quality (covered more extensively in Session 4, Building the Data Sets of Tomorrow).

As in most discussions about the use of electronic health records, there were follow-up comments about legal ramifications and confidentiality concerns. There is belief that such electronic data will become increasingly available, from such sources as all-payer databases, clinical trials, and CMS. This increasing access raises concerns about both legal issues of data linkage involving protected health information and respondents' willingness to provide such information when their health insurance is employer-based.

SESSION 3: Optimizing Health Survey Strategies

ORGANIZERS: Stephen Blumberg (National Center for Health Statistics), **Brad Edwards** (Westat), and **James Lepkowski** (University of Michigan)
CHAIR: Stephen Blumberg

The Use of Online Panels to Characterize the Management of Rare Diseases: The Case of Primary Immune Deficiency Diseases

John M. Boyle (Abt SRBI Inc.)

There are many rare or uncommon diseases in the United States whose management and treatment are largely unreported outside of clinical settings. The prevalence rates of these conditions are assumed to be too low for their inclusion in even the largest health surveys. In the absence of population-based assessments of these conditions, there are no reliable estimates of the characteristics of the affected individuals, management and treatment of the disease, or health outcomes in the general population.

The population prevalence for one such condition—primary immune deficiency disease (PIDD)—was established by a national random-digit-dialing (RDD) telephone survey of 10,000 households in 2005. This survey also unexpectedly suggested that only a minority of PIDD patients were being treated with immunoglobulin therapy, the standard of care for antibody disorders. However, the sample of patients in this survey was too small to reliably characterize the rate of treatment for the condition.

The current study was undertaken to test the hypothesis that primary immune deficiency diseases are currently undertreated in the general population. A national online panel was used as the most cost-efficient method for obtaining a reasonably large community sample of a rare population. Although online panels are not probability samples and exclude persons without Internet access, they offer large community-based samples that could provide useful assessments of the treatment of rare diseases outside of clinical settings. This paper examines the utility of this approach for one rare disease.

BACKGROUND

Primary immunodeficiency diseases (PIDD) represent more than 150 rare disorders that impair immunological defenses resulting in increased susceptibility to infections (Yong, 2009). The majority of patients have an antibody deficiency for which immunoglobulin therapy is the standard of care (Buckley, 2009). A patient organization—the Immune Deficiency Foundation (IDF)—has conducted surveys of PIDD patients and families from its "member" database for two decades (Abt SRBI, Inc., 2009; Schulman, Ronca, & Bucuvalas, Inc., 1999, 2003). These surveys have provided the most widely accepted population estimates of the characteristics of patients with these conditions and the management of these diseases in the U.S.

In order to estimate the prevalence of diagnosed primary immune deficiency diseases in the U.S., IDF undertook a national RDD household survey in 2005. This survey of 10,000 households, including nearly 30,000 individuals in those households, was large enough to establish a precise estimate of the prevalence of PIDDs in the population (Boyle, 2009). The prevalence survey also unexpectedly found that only 22% of PIDD patients were currently being treated with intravenous immunoglobulin (IVIG), compared to 67% in a 2002 survey of 1,526 PIDD patients from the IDF database. However, the number of PIDD cases in the prevalence survey was too small to reliably characterize the rate of treatment.

The primary objective of the 2010 online survey was to characterize the treatment of PIDD patients, particularly those with antibody deficiencies, based on a reasonably large, community based sample of patients. A minimum sample size of at least 100 PIDD patients with antibody disorders was sought to reliably characterize the current use of immunoglobulin therapy.

STUDY DESIGN: INTERNET SURVEY OF NATIONAL ONLINE PANEL

Since the prevalence survey yielded only 23 eligible patients out of 10,000 households, about 43,000 households would have to be screened to obtain 100 cases with PIDD patients. Approximately 60,000 households would need to be screened for 100 PIDD cases with antibody deficiency disorders. The cost to conduct a national probability sample of even 100 cases for such an uncommon condition would exceed the resources of most interested parties. Hence, a design alternative was needed to provide community-based estimates of treatment of patients with primary immune deficiency diseases.

Currently, the most cost-efficient method for obtaining a nationally distributed sample of a rare population is to conduct Internet-based screening of a general population online panel. Although online panels are not probability samples (although a few online panels are initially recruited from probability samples) and they exclude approximately one quarter of U.S. adults who do not use the Internet at home or other locations, they are designed to provide large samples whose demographic characteristics are representative of the population (AAPOR, 2010). Hence, an online panel provides a cost-efficient approach to exploring the characteristics of a low incidence subset of the general population.

SURVEY METHODS

A large national online general population panel with approximately 1,000,000 current members was selected to test the approach. A generic invitation to participate in a new Internet survey was sent to panel members as they became available for new surveys (e.g., completed or screened out of another survey). Those panel members willing to participate in a new survey were sent to a site where they were shown broad screening questions for available surveys. Based on their answers, panelists were designated as potentially eligible for these surveys. If the panelist was eligible for multiple available surveys, the low-incidence survey, like primary immune deficiency diseases, was given priority.

Panelists who qualified for the PIDD survey on the broad screening question were offered an invitation to click on a hyperlink that took them to a secure server maintained by IDF's survey contactor. The respondent was issued a personal identification number (PIN) as part of the hyperlink so that they could access their own questionnaire repeatedly until they completed the interview. If the selected panelist accessed the PIDD survey on the IDF contractor's server, the respondent saw a series of screening questions that were used to determine whether the respondent or another household or family member had been diagnosed with a primary immune deficiency disease. All patients with eligible PIDD diagnoses were queried about their condition, treatment, and health outcomes.

The online panelists were offered a small incentive (entry into a lottery for a small prize) to participate in any survey hosted by the Internet panel organization. This is a panel maintenance function rather than an inducement to participate in a particular survey. No additional incentive was offered for the PIDD treatment survey to minimize incentives for noneligible respondents to participate.

In addition to the requirement that someone in the household (or immediate family living outside of the household) had been diagnosed with one of 18 specific primary immune deficiency diseases, potential participants were deemed unqualified if (1) they reported more than five persons with PIDD in the household or in the immediate family outside of the household, (2) they reported three or more different PIDD diagnoses for individual, (3) they reported either of two rare non-PIDD diagnoses that were placed at the beginning of the PIDD diagnosis list, or (4) they reported combinations of diagnoses that were improbable. Further, the length of interviews was reviewed to determine if any were too short to be

legitimate (i.e., speedsters); the pattern of responses also was checked for invariant responses (i.e., straight lining); and only a limited number of "not sure" and "no answer" responses were acceptable. These steps were designed to eliminate potentially fraudulent respondents from the survey.

SURVEY OUTCOMES

The survey was conducted from March 8–31, 2010. A total of 859,379 unique panelists from a Census-balanced national online panel were sent generic invitations to participate in a new survey opportunity. A total of 114,934 panelists (13%) went to a "requirements" page and completed a broad PIDD screening question. Three percent of those who completed the screening question on the requirements page (3,487 panelists) reported a primary immune deficiency disease in the household or immediate family (Table 1).

Table 1. Outcomes of Online Panel Survey

ACTION	*n*	% of Previous Action	% of Total
Sent e-mail invitations to survey	**859,379**		100.000%
Went to screening page	114,934	13.40%	13.400%
Qualified on screening page	3,487	3.00%	0.040%
Went to main questionnaire	1,702	48.80%	0.020%
Qualified on diagnosis	159	0.09%	0.002%

Table 2. Outcomes of Survey Screen (*n* = 1,702)

OUTCOME	*n*	%
Good PIDD diagnosis	159	9.3%
Bad PIDD diagnosis	382	22.4%
No diagnosis given	130	7.6%
No PIDD in household or family	865	50.8%
No answer to screening question	166	9.8%

Of the 3,487 online panelists who reported a PIDD in their household or immediate family, about half (49%) accepted the invitation to participate in the survey and went to the IDF survey Web site. These 1,702 qualifying respondents who went to the site then were asked: "Has anyone currently living in your household ever been diagnosed with a primary immune deficiency disease, such as…?" These respondents also were asked: "Has anyone in your immediate family (parents, children or siblings) currently living outside of your household ever been diagnosed with a primary immune deficiency disease, such as…?"

A total of 728 respondents from the online panel reported a person with a primary immune deficiency disease living in their household or in their immediate family living outside of the household. The ages and genders were obtained for each PIDD living in the household and any PIDDs living outside of the household if there were no PIDDs in the household. For each PIDD patient, respondents were asked what specific types of primary immune deficiency that person had been diagnosed as having. A precoded answer list was presented on two screens that included 18 legitimate diagnoses of primary immune deficiency diseases, 13 nonlegitimate diagnoses, and an "other" (specify) category. Most of the legitimate diagnoses were presented on the first screen, along with a few nonlegitimate diagnoses.

Overall, among 1,702 persons who qualified on the requirement question and went to the survey website, only 9% reported a legitimate PIDD diagnosis in the household or immediate family. Twice as many (22%) claimed a PIDD in the household or immediate family but reported a nonqualifying diagnosis. Another 8% reported a PIDD in the household or family but did not give any diagnosis. Half (51%) reported no PIDD in the household or family. One in ten (10%) did not answer any of the qualifying questions after going to the survey Web site (Table 2).

Table 3. Non-PIDD Diagnoses (*n* = 247)

DIAGNOSIS	*n*	%
AIDS	9	4%
Autoimmune Hemolytic Anemia	5	2%
Auto-Immune Lymphoproliferative Syndrome	1	0%
Cancer/Leukemia	12	5%
Crohn's or Inflammatory Bowel Disease	27	11%
Diabetes	23	9%
Fibromyalgia	49	20%
Hashimoto's Disease	12	5%
ITP	9	4%
Lupus	44	18%
Multiple sclerosis	22	9%
Rheumatoid arthritis	44	18%
Other	107	43%

Table 4. PIDD Diagnoses (*n* = 160)

DIAGNOSIS	*n*	%
Agammaglobulinemia	**7**	**4%**
Ataxia Telegectesia	**2**	**1%**
Chronic Granulomatous Disease	5	3%
Combined Immunodeficiency	**20**	**13%**
Common Variable Immunodeficiency	**42**	**26%**
Complement	5	3%
DiGeorge Syndrome	**1**	**1%**
Hereditary Angiodema	1	1%
Hyper IgM	**3**	**2%**
IgG Subclass Deficiency	**23**	**14%**
Selective IgA Deficiency	21	13%
Severe Combined Immunodeficiency	**10**	**6%**
SCN	4	3%
Selective Antibody Disorder	**8**	**5%**
Wiskott Aldredge Disease	**2**	**1%**
X-linked P	1	1%
Mixed	5	3%
All Antibody Disorders	**118**	**74%**

Excluding two very uncommon conditions (alpha-one antitrypsin deficiency and alagile syndrome) that were placed at the beginning of the first screen to identify fraudulent respondents, there were 247 patients who were reported as exclusively non-PIDD diagnoses as primary immune deficiency diseases in the household or family (Table 3). Most commonly, these conditions were fibromyalgia (20%), lupus (18%), rheumatoid arthritis (18%), Crohn's disease or irritable bowel syndrome (11%), multiple sclerosis (9%) and diabetes (9%). Similarly, the most commonly reported non-PIDD diagnoses in the 2005 national telephone prevalence survey were lupus, fibromyalgia, diabetes, rheumatoid arthritis, arthritis (not specified), multiple sclerosis, and Crohn's disease. Most of these non-PIDD conditions are auto-immune conditions, so respondent confusion is understandable.

Among the 160 patients with PIDD from the Internet survey, the most common diagnosis was Common Variable Immunodeficiency or CVID (26%, Table 4). The three next most common diagnoses were IgG Subclass Deficiency (14%), Selective IgA Deficiency (13%) and Combined Immunodeficiency (13%). The other diagnoses reported by more than two percent of cases were: Severe Combined Immunodeficiency or

SCID (6%), Selective Antibody Deficiency (5%), Agammaglobulinemia (4%), Chronic Granulomatous Disease or CGD (3%), Complement Deficiency (3%) and Severe Congenital Neutropenia or SCN (3%). The PIDD diagnoses reported by the 23 patients in the 2005 prevalence survey were also CVID, Selective IgA Deficiency, IgG Subclass Deficiency, SCID, Agammaglobulinemia and CGD.

Three out of four of the PIDD patients in the Internet survey (74%) reported an antibody deficiency diagnosis for which immunoglobulin therapy is the recommended treatment (Table 4). This includes IgG subclass deficiency where immunoglobulin therapy is more controversial. If IgG subclass deficiency is excluded, at least 59% of the diagnoses of PIDDs in the online survey would be appropriate for immunoglobulin therapy. These rates of antibody disorders among PIDD patients are similar to the 2005 telephone prevalence survey where 66% of the diagnoses were suitable for immunoglobulin therapy when including IgG subclass deficiency, and 57% if IgG subclass deficiency is excluded.

Among the 159 respondents who reported qualified PIDD diagnoses in the household or family, only 147 completed the full interview. These respondents included patients (39%), parents (25%), spouses or partners (10%), siblings (16%) or other relatives (8%) of PIDD patients. Only 2% were nonrelatives of the patient and another 2% did not specify their relationship to the patient (Table 5). These 147 respondents reported a total of 160 patients with legitimate PIDD diagnoses in the household or immediate family. The geographic distribution of the PIDD patient population from the Web survey is almost identical with the U.S. adult population distribution by Census division in 2009 (Table 6).

There were 144 respondents from the Web survey who reported one or more legitimate PIDD cases living in their household. If the 144 households with a qualified PIDD diagnosis is divided by the full 114,934 panelists who completed the initial requirement question about primary immune deficiency disease, it would yield a household rate of PIDD of 1 in 798 households. However, if those who reported a PIDD on the requirements page but did not go to the IDF Internet survey had the same rate of eligibility as those who did, then we would expect a total of 295 eligible respondents. This would mean a prevalence rate of 1 in 390 households. These two estimates of the household prevalence of PIDD from the 2010 online panel survey bracket the estimate of 1 PIDD in 555 households from the 2005 telephone prevalence survey.

Table 5. Relationship to Patient

RELATIONSHIP	%
Patient	39%
Parent	25%
Spouse or partner	10%
Brother or sister	16%
Other relative	8%
Other nonrelative	2%
No answer	2%

Table 6. Geographic Distribution of PIDD Patients & Total U.S. Population

REGION	U.S. Adult Population 2009	Patients (*n* = 144)
New England	5%	6%
Mid Atlantic	14%	16%
East North Central	15%	16%
West North Central	7%	6%
South Atlantic	19%	17%
East South Central	6%	6%
West South Central	11%	8%
Mountain	7%	6%
Pacific	16%	17%

In the 2005 telephone prevalence survey, respondents were asked whether the PIDD patient was currently being treated with intraveneous immunoglobulin (IVIG), and, if not, whether they had ever been treated with IVIG. Since the prevalence survey, the use of subcutaneous immunoglobulin (SCIG) has become much more widespread for PIDD in the United States. In addition, intramuscular immunoglobulin (IMIG) was the standard of treatment before the adoption of IVIG. Hence, in the 2010 Internet survey, respondents were asked whether the PIDD patient had ever used IMIG, IVIG, or SCIG. For each form of immunoglobulin treatment they reported the PIDD patient had ever used, they were asked whether the patient was still using that treatment. Hence, the measurement of lifetime and current use of immunoglobulin treatment was broader in the 2010 Internet survey than the prevalence survey, which focused exclusively on what was then the most common form of treatment—IVIG.

Among the 23 patients with a PIDD diagnosis in the 2005 national telephone prevalence survey, only 44% reported they had ever been treated with IVIG for their condition. Among the 160 patients with PIDD diagnoses in the online survey, 36% reported they had ever been treated with IVIG. However, an identical 44% of PIDD patients in the 2010 Internet survey reported they have ever been treated with IVIG or SCIG, which is a more appropriate comparison because many PIDD patients have switched to SCIG from IVIG since 2005. When also including intramuscular immunologlobulin, the **lifetime use** of any form of immunoglobulin (IMIG, IVIG, or SCIG) is 58% in the Internet survey.

Even when including IVIG, SCIG, and IMIG, less than half (48%) of PIDD patients in the Internet survey report **current treatment** with immunoglobulin therapy. The difference in estimates of current immunoglobulin treatment between the 2005 telephone prevalence survey (22%) and the Internet survey (48%) is large enough to be outside of the expected pooled error based on sample size (Table 7). However, the Internet survey estimate is based on a broader definition of immunoglobulin therapy (i.e., IMIG, SCIG, and IVIG) compared to the 2005 telephone survey. And, the larger estimate of current immunoglobulin use in the 2010 Internet survey (48%) is still well below the estimates of current IVIG use (67% in 2002 and 74% in 2007) in two large surveys of PIDD patients conducted by IDF from its database. Even more importantly, only half of patients with specific PIDD diagnoses for which immunoglobulin is the recommended treatment (51%) reported currently being treated with any form of immunoglobulin in the 2010 Internet survey (Table 7).

Table 7 also shows that the relatively low level of current immunoglobulin therapy among patients from the online panel is paralleled by their attitudes toward immunoglobulin treatment. Only 22% of patients in the online survey felt that immunoglobulin therapy was very effective (Table 7). Only 24% of patients felt that immunoglobulin therapy was very safe. And little more than half of these patients felt that their primary doctor strongly (29%) or somewhat (27%) favored treating them with immunoglobulin. The patient attitudes about immunoglobulin treatment are similar to those found among primary care doctors in the IDF surveys of pediatricians and family practitioners.

Table 7. Immunoglobulin Treatment

	%
Current Treatment with Immunoglobulin, by All Patients	
IVIG 2002 IDF Patient Survey (*n* = 1,526)	67%
IVIG 2005 RDD Telephone Survey (*n* = 23)	22%
IVIG 2010 Web Survey (*n* = 160)	29%
IVIG & SCIG 2010 Web Survey (*n* = 160)	35%
IVIG, SCIG & IMIG 2010 Web Survey (*n* = 160)	48%
IVIG & SCIG 2007 IDF Patient Survey (*n* = 1,351)	74%
Current Treatment with Immunoglobulin by Antibody Deficient Patients	
IVIG, SCIG & IMIG 2010 Web Survey (*n* = 119)	51%
Effectiveness of Immunoglobulin Therapy (*n* = 147)	
Very effective	22%
Somewhat effective	44%
Not too effective	9%
Not sure	25%
How Safe is Immunoglobulin Therapy (*n* = 147)	
Very safe	24%
Somewhat safe	41%
Not too safe	10%
Not safe at all	1%
Not sure	25%
Doctor's Attitudes about Immunoglobulin (*n* = 147)	
Strongly favors	29%
Somewhat favors	27%
Neither favors nor opposes	16%
Somewhat opposes	5%
Strongly opposes	1%
Not sure	22%

Table 8. Respondent Health Issues: 2010 Web Survey vs. 2002 IDF Survey

	2010 WEB		2002 IDF
	n	%	%
Acute Conditions in Last month	**(*n* = 147)**		**(*n* = 1,526)**
Bronchitis	53	36%	45%
Candida	20	14%	17%
Diarrhea (repeated)	54	37%	34%
Ear infections (repeated)	35	24%	25%
Eye infections	16	11%	16%
Lymphopenia	8	5%	3%
Malabsorption	9	6%	8%
Neutropenia	5	3%	3%
Pneumonia	29	20%	17%
Sepsis	7	5%	2%
Urinary infections	37	25%	17%
Current Health Status	**(*n* = 147)**		**(*n* = 1,526)**
Excellent	10	7%	8%
Very good	11	7%	21%
Good	48	33%	30%
Fair	55	37%	28%
Poor	17	12%	10%
Very poor	6	4%	2%
No answer	—	—	1%
Activity Limitation	**(*n* = 147)**		**(*n* = 1,526)**
No limitation	25	17%	20%
Slight limitation	48	33%	29%
Moderate limitation	50	34%	25%
Severe limitation	24	16%	14%
No answer	—	—	2%
Hospitalization in Past Year	**(*n* = 147)**		**(*n* = 1,526)**
Yes	57	39%	30%
No	87	59%	69%
Not sure	3	2%	1%

The prevalence of specific acute health conditions in the past 12 months was remarkably consistent between the 2002 IDF member survey and the 2010 online panel for bronchitis (45%-36%), Candida (17%-14%), repeated diarrhea (34%-37%), repeated ear infections (25%-24%), eye infections (16%-11%), lymphopenia (3%-5%), malabsorbtion (8%-6%), neutropenia (3%-3%), pneumonia (17%-20%), and sepsis (2%-5%, Table 8). Although the populations from the member surveys and online panel look similar in terms of specific conditions, their current health outcomes look different. Only 15% of patients from the online panel are reported as being in excellent or very good health, compared to 28% in the 2002 member survey. Similarly, 50% of the patients from the online survey are reported as having moderate or severe activity limitations as result of their health, compared to only 39% of patients from the member survey. Nearly two out of five patients in the online survey (39%) reported being hospitalized in the past 12 months, compared to 30% from the member survey. These differences in health outcomes may be related to differences in rates of treatment with immunoglobulin between IDF member surveys and the community-based online survey, although the survey suggests that sicker patients in the online panel are more likely to be treated with immunoglobulin.

Table 9. Immunologist Location

	%
Immunologist Location, by All Patients (*n* = 147)	
University hospital or medical center	29%
Nonuniversity hospital	24%
Private practice	28%
Other	3%
No Immunologist	14%
Not sure	3%
Current IG Treatment, by Immunologist Location	
University hospital or medical center (*n* = 52)	58%
Nonuniversity hospital (*n* = 38)	60%
Private practice (*n* = 42)	43%
No immunologist (*n* = 20)	20%
Not sure (*n* = 4)	0%

Table 10. Contact with Immune Deficiency Foundation & Current IG Treatment

	%
Knowledge of IDF (*n* = 147)	
Heard of them	41%
Never/Not sure heard of them	59%
How Heard of IDF (*n* = 147)	
Told about by others	8%
Seen patient information	14%
Visited Web site	22%
Called them	5%
Get newsletter	9%
Other	2%
Not sure	1%
No contact/Only this survey	8%
Current IG Treatment, by Contact with IDF	
Never/not sure heard of them (*n* = 94)	40%
Heard of IDF (*n* = 66)	59%
Heard of IDF/No newsletter (*n* = 52)	50%
Get newsletter (*n* = 14)	93%

One of the goals of the online panel was to reach a national sample of PIDD patients, including those who might not be seen in academic medical centers. In the 2010 Internet survey, most PIDD patients reported seeing an immunologist at least once a year. However, only 29% of these PIDD patients are seen by an immunologist located in a university hospital or medical center (Table 9). The location of the PIDD patient's immunologist has a substantial effect on the patient's current and lifetime use of immunoglobulin therapy. The proportion of PIDD patients that are currently using immunoglobulin therapy, including IMIG, IVIG and SCIG, is 58% for patients who are seen by an immunologist in a university hospital and 60% of those seen by an immunologist in a non-university hospital. However, current use of immunoglobulin falls to 43% of patients seeing an immunologist in private practice or an HMO, and 20% of those not seeing an immunologist. Hence, immunoglobulin treatment rates that are more consistent with treatment guidelines are found for patients being followed by hospital-based immunologists.

A second related goal for the online panel was to reach a community-based population of PIDD patients who were not part of the membership database for the patient organization. Only two out of five patients

from the online panel (41%) reported they had ever heard of IDF (Table 10), and less than one in ten (9%) received the IDF newsletter sent to everyone in the organization's database.

The online survey also found a significant difference in immunoglobulin treatment between patients who were connected to IDF and those who were not. Nearly three out of five PIDD patients who have heard of the IDF (59%) currently are using immunoglobulin therapy for their condition. Nine out of ten patients who report receiving the IDF newsletter (93%) currently are being treated with immunoglobulin. These rates of current immunoglobulin (IVIG, SCIM, IMIG) treatment by patients in contact with IDF in the 2010 Internet Survey are closer to the rate of current IVIG use (70%) reported in the IDF patient survey from their database. By contrast, only 40% of patients who have not heard of IDF are currently taking immunoglobulin therapy (Table 10). These findings seem to confirm the hypothesis that PIDD patients in the general community not connected to IDF or major medical centers and hospitals are being undertreated with immunoglobulin therapy compared to the clinical care guidelines for these conditions.

CONCLUSIONS

A rare disease is defined in the Rare Disease Act of 2002 as "any disease or condition that affects less than 200,000 persons in the United States" or about 1 in 1,500 persons. This definition of rare disease, however, is derived from a legal definition of an "orphan disease," which has not been adopted by the pharmaceutical industry for the development of medications because the size of the affected population is too small to be commercially viable. From the standpoint of health research, we might define a rare or uncommon disease as one of which prevalence is too low to make population-based assessments of the disease and its treatment feasible under most conditions. For example, there are very few examples of health surveys conducted in the U.S. of medical conditions with prevalence rates less than 1%. As a result, there are thousands of medical conditions for which little is known about the management and treatment of the condition in the general population, outside of controlled clinical trials.

Primary immune deficiency diseases represent an example of an uncommon or rare disease for which community-based assessments of disease management are needed. The 2005 IDF prevalence telephone survey was conducted to estimate the prevalence of this condition in the U.S. A sample size of 10,000 households was sufficient to estimate the prevalence of this relatively rare condition but much too small to generate a sample of diagnosed PIDD patients that could reliably characterize their treatment. However, the findings from the small probability sample suggested for the first time that there might be a serious problem of undertreatment among patients diagnosed with PIDD. Treatment rates in other surveys conducted by IDF from its database were consistent with clinical guidelines, but the patients known to a patient organization may not be typical of the general population.

The current study was designed to test the hypothesis that a substantial number of PIDD patients in the U.S. were not being treated with immunoglobulin therapy as recommended by current clinical guidelines. In order to test this hypothesis, a national sample was needed large enough to provide a reasonable confidence interval about estimates (assuming a probability sample). It also needed to be a community-based sample so that it could represent the patient population that is not being serviced by nor could be reached through patient organizations and major medical centers. Finally, the study design needed to be sufficiently cost efficient to be supported by patient organizations or other interested parties without the resources of the federal government or major pharmaceutical companies. A large Census-balanced online panel appeared to meet the requirements to test this hypothesis

Online panels have a number of well-known limitations, including coverage of persons without Internet access and overrepresentation of the population who are more experienced and comfortable in online transactions. They are based on a self-selected sample rather than a true probability sample. There are well-known demographic biases (e.g., age, race) associated with online panels. Response rates are extremely low. There are also problems of survey gaming to obtain incentives, which need to be controlled in the survey design. Nonetheless, the judicious use of a large Census-balanced online panel appeared to be the only practical way to obtain a community sample of a rare population large enough to answer some critical questions about disease treatment in the general population.

We believe that the findings of this Internet survey support the hypothesis that immunoglobulin therapy, the standard of care for most patients with PIDD, is being underutilized in the general patient population, particularly outside of major medical centers and hospital-based immunology practices. Moreover, we believe that the findings from this study demonstrate the potential value of the approach for other rare conditions. The online panel was large enough to generate a sample of approximately 150 patients for a condition of which prevalence is estimated at 1 in 1,250 persons. The sample was geographically distributed in proportion to the population. The distribution of specific diagnoses and specific types of infections in the past year were consistent with previous surveys of this population. At the same time, the patient sample provided by the online panel represented a community sample much broader than the IDF membership or patients who might be recruited at major medical centers. Nine out of ten cases would not have been in the relatively large patient database maintained by the patient organization, and only a minority was being seen for their condition in major medical centers.

The patients from the online panel who were not in the IDF database and not being seen by hospital-based immunologists were less likely to be currently treated with immunoglobulin, explaining much of the difference in treatment estimates from both the telephone and Internet surveys and previous "membership" surveys. The Internet survey also finds a PIDD patient population that tends to be sicker (i.e., general health rating, activity limitations, and hospitalizations) than the population described in earlier IDF surveys from its patient database. These poorer health outcomes would be consistent with undertreatment for the condition. Hence, monitoring the treatment and health outcomes of rare or uncommon diseases outside of the university hospitals and major medical centers may identify treatment gaps with profound effects on public health and quality of life. Although no substitute for probability samples, this study suggests that online panels may play a useful role in the monitoring of treatment and health outcomes in rare diseases where adequate community samples cannot be obtained from population-based sampling frames.

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Design of Health Surveys for Public Health Emergencies: Early Responder Bias in the National 2009 H1N1 Flu Survey[1]

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INTRODUCTION

Design of surveillance systems for public health emergencies must consider the content, frequency, and turnaround time of information needed, use of existing systems, need for development of new systems, and possible tradeoffs in data quality and precision given time and resource constraints (Link, Mokdad, & Balluz, 2007). In response to the 2009 influenza A (H1N1) (pH1N1) pandemic, the Centers for Disease Control and Prevention (CDC) developed systems to monitor pH1N1 disease and the use, safety, and effectiveness of pH1N1 vaccine (Schuchat, Bell, & Redd, 2011). The goals for monitoring pH1N1 vaccination included the use of surveys to provide weekly estimates of the proportion of target groups vaccinated, place of vaccination, reasons for non-vaccination, and opinions about risk of influenza and safety and effectiveness of influenza vaccination (Singleton, 2010). Given the uncertainty regarding the types of influenza viruses that would circulate in the upcoming 2009–2010 influenza season, both monovalent pH1N1 and trivalent seasonal influenza vaccines were recommended for various target groups (Fiore et al., 2009; National Center for Immunization and Respiratory Diseases, 2009).

The National 2009 H1N1 Influenza Survey (NHFS), a dual landline and cell telephone survey, was conducted October 2009–June 2010 to provide weekly estimates for pH1N1 and seasonal influenza vaccinations (Singleton, Santibanez et al., 2010). Data from NHFS and other systems were used in development of public messages about the vaccination campaign, to help assess safety and effectiveness of the vaccine, and to provide feedback to states on their vaccination programs (CDC, 2010; Ding et al., 2010; Gargiullo et al., 2009; Lu et al., 2010; Velozzi et al., 2010). Evaluation of this enhanced surveillance system is needed to identify areas of improvement for influenza vaccination surveys during future pandemic and inter-pandemic seasons.

Nonresponse bias is an important survey attribute to assess, particularly in rapid response surveys, which may have lower responses rates than routine surveys. Comparison of survey respondents by level of effort (e.g., time or number of call attempts to complete) is one readily available approach for assessing nonresponse bias (Groves, 2006). These studies assume a continuum of resistance with nonresponders represented by hardest to reach respondents (Biemer & Link, 2008; Keeter, Kennedy, Dimock, Best, & Craighill, 2006). Such studies are also useful for evaluating potential change in validity of survey estimates that would result by reducing the effort expended to obtain interviews. This information is relevant for improving cost-efficiency, and for decision making in special circumstances when timely information is needed and some level of systematic error in estimates can be tolerated or accounted for based on past experience.

[1] The findings and conclusions in this report are those of the authors and do not necessarily represent those of the Centers for Disease Control and Prevention.

The purpose of this paper is to compare early and late responders to the NHFS to assess potential change in validity of survey estimates if effort to obtain interviews had been reduced and to assess nonresponse bias in the NHFS in a level of effort analysis comparing early and late respondents. This paper expands on previous preliminary analysis of early responder bias in the NHFS (Singleton, Copeland, Ganesh et al., 2010).

METHODS

NHFS data collected October 2009–June 2010 were used for this analysis (56,656 completed adult interviews and 14,652 completed interviews for children). The CDC contracted with NORC at the University of Chicago to design and implement the NHFS. The NHFS consisted of a national random-digit–dial survey based on a rolling weekly sample of landline and cellular telephones contacted to identify residential households. For the landline sample, within each contacted NHFS sample household, one adult was randomly selected for interview, and the parent or guardian of one randomly selected child (if present) was selected for interview. For the cell sample, the target was owners of privately used cell phones and an interview was attempted if the person answering was ≥18 years. Monthly targets for the NHFS sample were established to achieve approximately 6,000 total completed adult interviews (4,889 from landline and 1,111 from cell-phone-only or cell-phone-mainly households). The cell phone sample was screened for households with wireless only service (cell-only) or households with both cellular and landline service who responded "somewhat unlikely" or "not at all likely" to the question, "Thinking just about the landline home phone, not your cell phone, if that telephone rang and someone was home, under normal circumstances how likely is it that it would be answered?" (cell-mainly). The landline NHFS sample was augmented with a sample of children age less than 18 years identified during screening for the National Immunization Survey (NIS); the NIS child data were not analyzed for this paper. Sample for the NHFS was released to the NORC calling center on a weekly basis, with "week" defined as Sunday through Saturday, and each released panel remaining active for five weeks. Each sampled telephone number continued to be called across the five weeks until the number was resolved as nonresidential, there was a confirmed refusal, or a completed interview was obtained. A minimum of eight call attempts were made to each sampled telephone number, more if there was evidence the number was associated with a household. Completed interviews obtained within a survey week (regardless of the panel to which they belonged) then were used in generating the estimates for that survey week. The estimates for a given survey week were thus based upon completed interviews from five panels that included both early and late responders. Sample weights were developed with adjustments for probability of selection, multiple phone lines per household, age-specific national proportion of the population estimated to be in landline vs. cell-only/mainly households, and ratio adjustment to Census population estimates by age group, gender, race/ethnicity and state of residence. The response rates (type RR3) for the first 21 completed weekly panel releases were 35% for the landline sample (79% resolution, 100% screening, 44% interview completion) and 27% for the cell-only/mainly sample (56% resolution, 86% screening, and 56% interview completion (American Association of Public Opinion Research, 2011).

Respondents were classified by week since sample release (WSR), from one to five weeks, and grouped into early (WSR = 1, 2) and later (WSR = 3, 4, 5) respondents. The median number of call attempts for completed interviews across landline and cell-only/mainly samples ranged from 2, 5–6, 8–10, 11–13, and 14–15 for weeks 1, 2, 3, 4, and 5 since release, respectively. Respondent characteristics examined included age group, race/ethnicity, sex, region, level of education, pH1N1 and seasonal influenza vaccination target groups, health care worker status, household income, Metropolitan Statistical Area status, housing tenure, and employment

status. Influenza-vaccine-related outcomes examined include receipt of pH1N1 vaccination since October 2009, receipt of seasonal influenza vaccination since August 2009, opinions about safety and effectiveness of influenza vaccines, risk of influenza illness if not vaccinated, and level of concern about "swine flu."

All analyses were conducted with SUDAAN software to account for the complex survey design.

Associations between WSR and respondent characteristics were assessed by chi-square tests, overall and by source of sample (landline vs. cell-only/mainly). The prevalence of influenza-vaccine-related outcomes for early vs. later responders were compared, overall and stratified by sample source. Because vaccination and other outcomes varied over time, logistic regression models were fit for each outcome and sample source, with main effects for WSR group (early, later) and interview week. Because of incomplete time for full five-week follow-up, the first four weeks of interview data were excluded from this analysis. Adjusted differences in outcome proportions were estimated from predictive marginals obtained from the logistic regression models. The cumulative proportion of persons vaccinated by end of May 2010 was estimated using the Kaplan-Meier procedure based on reported month of vaccination as the time unit. Vaccination coverage estimates were compared between early and later responders.

To assess the potential increase in nonresponse bias if the survey had been restricted to early respondents, differences in influenza vaccination coverage between reweighted early responders and all responders were estimated. Comparisons were made for pH1N1 and seasonal vaccination for adults and children, and for adults stratified by race/ethnicity, age, target group, and healthcare personnel. To reweight the early responder sample, the sample restricted to early responders was post-stratified to the Census population controls.

To assess overall nonresponse bias in final survey results, the difference in estimated vaccination coverage based on all respondents and later respondents was multiplied by the nonresponse rate. Vaccination coverage estimates were examined for each of the five weeks since sample release to assess for possible dose-response (larger difference between estimates for 1st week vs. later week responders, as week since release increases), to determine if WSR = 5 responders or WSR = 3, 4, or 5 should be used to represent nonresponders.

RESULTS

Of the 56,656 adult respondents, 53.7% responded by the first week since sample release, 23.3% in the 2nd week, 12.5% in the 3rd week, 6.7% in the 4th week, and 3.8% in the 5th week. Thus, 77% were classified as early and 23% as later respondents. The distribution by WSR did not differ between landline (80.5% of respondents) and cell-only/mainly samples (19.5%). For the landline sample, there were differences between early and later responders for 13 of 16 characteristics, with the largest differences by age (25.5% of early responders ≥65 years vs. 17.8% of later respondents), race/ethnicity (non-Hispanic White only 75.8% vs. 68.9%), having a child in the household (34.8% vs. 40.9%), employment status (employed, 50.8% vs. 56.9%; retired, 23.8% vs. 16.3%), and member of seasonal target group (72.5% vs. 66.4%, Table 1). Fewer characteristics differed by responder status for the cell-only/mainly sample, and effects were different for age and sex compared to the landline sample (in the cell-only/mainly sample, early responders were more likely to be 18–24 years and male). Overall, the cell-only/mainly respondents were more likely than landline respondents to be younger, non-White, interviewed in Spanish, male, have a child in the household, live in the principal city of a metropolitan statistical area, live below the poverty level, rent their dwelling, be employed, have no health insurance, not have a chronic medical condition, be in the pH1N1 target group, and not be in the seasonal target group.

Table 1. Comparison of Respondent Characteristics between Early & Later Responders, by Sample Source, National 2009 H1N1 Flu Survey (standalone component)

CHARACTERISTIC	LANDLINE		CELL-ONLY/MAINLY	
	Early Responders (*n* = 35,079)	Later Responders (*n* = 10,520)	Early Responders (*n* = 8,540)	Later Responders (*n* = 2,517)
Age (years)				
18–24	7.7†	12.4†	21.2‡	15.1‡
25–29	5.1	6.4	16.2	16.1
30–34	6.3	6.4	12.1	14.2
35–44	16.5†	19.4†	19.1	21.1
45–49	10.0	9.5	9.8	11.7
50–54	10.3	10.7	8.0	8.1
55–64	18.6	17.4	9.6	9.5
≥65	25.5†	17.8†	3.9	4.2
Race/Ethnicity				
Hispanic	9.1†	13.2†	20.8	22.0
Non-Hispanic, Black only	9.8	12.2	13.3	15.4
Non-Hispanic, White only	75.8†	68.9†	57.7	54.0
Non-Hispanic, other or multiple races	5.3	5.8	8.2	8.6
Interview Language				
English	96.1†	91.2†	90.0‡	80.5‡
Spanish	2.8†	6.7†	8.7‡	16.3‡
Other language	1.1†	2.2†	1.3‡	3.2‡
Sex				
Male	42.6†	46.1†	56.8‡	52.3‡
Female	57.4†	53.9†	43.2‡	47.7‡
Child in Household				
Yes	34.8†	40.9†	40.0	43.2
No	65.2†	59.1†	60.0	56.8
Region				
I. CT, ME, MA, NH, RI, VT	5.2	5.3	3.6	3.7
II. NJ, NY	9.8	10.6	7.7‡	11.0‡
III. DE, DC, MD, PA, VA, WV	9.8	10.5	8.5	10.1
IV. AL, FL, GA, KY, MS, NC, SC, TN	18.9	18.6	22.1	19.6
V. IL, IN, MI, MN, OH, WI	18.1	17.2	15.2	14.1
VI. AR, LA, NM, OK, TX	10.2	10.4	16.1	14.7
VII. IA, KS, MO, NE	4.7†	3.8†	4.6‡	2.8‡
VIII. CO, MT, ND, SD, UT, WY	3.3	3.0	3.5	3.3
IX. AZ, CA, HI, NV	15.9	16.1	14.7	17.1
X. AK, ID, OR, WA	4.1	4.5	4.2	3.7
Metropolitan Statistical Area				
MSA, principal city	28.8	29.8	41.4	39.2
MSA, not principal city	53.0	54.4	44.6	48.7
Non-MSA	18.2†	15.8†	14.0	12.0
Education Level				
<12 years	10.5	11.6	13.9	13.1
12 years	22.1	22.3	21.2	25.6
Some college	27.2	27.3	30.2	30.4
College graduate	40.2	38.8	34.7	30.9
Household Poverty Status				
Above poverty, annual income >$75,000	29.1	29.7	22.0‡	17.1‡
Above poverty, annual income ≤$75,000	44.8†	40.2†	44.0	41.0
Below poverty	9.9	10.3	17.5	17.8
Unknown	16.3†	19.8†	16.4‡	24.2‡

Table 1, cont'd.

CHARACTERISTIC	LANDLINE Early Responders (*n* = 35,079)	LANDLINE Later Responders (*n* = 10,520)	CELL-ONLY/MAINLY Early Responders (*n* = 8,540)	CELL-ONLY/MAINLY Later Responders (*n* = 2,517)
Own or Rent Dwelling				
Own	79.9†	77.9†	48.2	50.9
Rent	17.7	18.3	46.6	45.0
Other	2.5†	3.8†	5.3	4.1
Employment Status				
Employed	50.8†	56.9†	65.9	66.6
Out of work	6.9	7.2	10.2	10.2
Homemaker	8.6	8.0	4.4	5.7
Student	4.2†	6.8†	9.9	8.4
Retired	23.8†	16.3†	4.5	4.6
Unable to work	5.7	4.7	5.2	4.4
Health Insurance Status				
Insured	89.0	87.7	72.5	67.1
No insurance	11.0	12.3	27.5	32.9
Chronic Medical Condition*				
No	71.7†	74.3†	80.5	79.5
Yes	28.3†	25.7†	19.5	20.5
pH1N1 Target Group**				
No	63.0†	58.7†	49.4	53.4
Yes	37.0†	41.3†	50.6	46.6
Seasonal Target Group¶				
No	27.5†	33.6†	48.7	51.0
Yes	72.5†	66.4†	51.3	49.0
Works in Health Care Setting				
No	89.4	89.7	87.0	86.6
Yes	10.6	10.3	13.0	13.4

† For landline sample, statistically significant association between responder status (early vs. later) and characteristic (Adjusted Wald F *p*-value < 0.05), and statistically significant difference in prevalence of characteristic level between early and later respondents by post-hoc t-test ($p < 0.05$).

‡ For cell-only/mainly sample, statistically significant association between responder status (early vs. later) and characteristic (Adjusted Wald F *p*-value < 0.05), and statistically significant difference in prevalence of characteristic level between early and later respondents by post-hoc t-test ($p < 0.05$).

* Chronic medical conditions that a health professional has reported to respondent, including current asthma, other lung condition, heart condition, diabetes, kidney condition, sickle cell or other anemia, neurological or neuromuscular condition, liver condition, or weakened immune system.

** Initial H1N1 target group (among persons ≥18 years) included all persons 18–24, persons 25–64 years with a chronic medical condition, pregnant women, health care personnel, and persons living with or providing care for infants <6 months.

¶ Seasonal target group (among persons ≥18 years) included all persons 18 years, persons 19–49 with a chronic medical condition, pregnant women, health care personnel, persons living with or providing care for infants <6 months and others at high risk for influenza-related complications, and all persons ≥50.

Comparing influenza-related opinions and vaccination status, some statistically significant differences by responder status were found. For the landline sample, early responders had higher adjusted pH1N1 and seasonal vaccination coverage than later responders, by 1.6 and 2.2 percentage points, respectively (Table 2). Early responders had a 2.2 percentage point higher prevalence than later responders of reporting they had very or somewhat high chances of seasonal flu sickness if not vaccinated for the landline sample, while for the cell-only/mainly sample, prevalence was 4.3 percentage points lower for early responders. For the cell-only/mainly sample, early responders were also less likely to report they were very or somewhat worried about getting sick from seasonal flu vaccine.

When comparing influenza vaccination coverage as of end of May 2010 between early and later responders by age, race/ethnicity, and target groups, most differences were not significant; however, some statistically significant differences were found, ranging from 7.3 percentage point lower seasonal vaccination coverage for Hispanic adults to 15.0 percentage points higher pH1N1 coverage among non-Hispanic black only children (Table 3). When comparing reweighted early to all responders, differences were reduced substantially; in all subgroups examined, the point estimate for reweighted early responders fell within the 95% confidence interval for all respondents.

Table 2. Comparisons of Adjusted Prevalence* (%) of Influenza-Related Outcomes between Early & Later Responders, National 2009 H1N1 Flu Survey (standalone component)

	LANDLINE SAMPLE			CELL-ONLY/MAINLY SAMPLE		
OUTCOME	Early Resp. (*n* = 35,079)	Later Resp. (*n* = 10,520)	Early – Later	Early Resp. (*n* = 8,540)	Later Resp. (*n* = 2,517)	Early – Later
Very concerned about H1N1 flu	17.1	18.1	–1.0	17.2	18.7	–1.5
H1N1 flu vaccination very or somewhat effective in preventing H1N1 flu	72.6	72.8	–0.2	72.1	70.6	1.5
Very or somewhat high chances of H1N1 flu sickness if not vaccinated	25.9	25.8	0.2	28.4	28.5	–0.1
Very or somewhat worried about getting sick from H1N1 flu vaccine	31.0	32.0	–1.0	33.5	36.6	–3.1
Received H1N1 vaccination	21.4	19.8	1.6†	16.7	14.8	1.8
Seasonal flu vaccination very or somewhat effective in preventing seasonal flu	82.2	81.3	0.9	77.9	78.3	–0.4
Very or somewhat high chances of seasonal flu sickness if not vaccinated	39.6	37.4	2.2†	36.8	41.1	–4.3†
Very or somewhat worried about getting sick from seasonal flu vaccine	25.9	27.2	–1.4	28.5	33.9	–5.4†
Received seasonal flu vaccination	46.9	44.7	2.2†	30.2	30.8	–0.6

* Adjusted prevalence determined from predictive marginal of logistic regression model with outcome as dependent variable and main effects for responder status (early vs. later) and week of interview. Excludes first four weeks of interviews.
† Statistically significant difference between adjusted prevalence of outcome between early and later responders.

To evaluate nonresponse bias by level-of-effort, differences in vaccination coverage estimates for all minus later respondents (from Table 3) were multiplied by the nonresponse rate (67.8%, calculated as the weighted average of landline and cell-only/mainly CASRO rates, using the weighted percent of the population in landline households of 64.6%). Estimated nonresponse bias across the 44 vaccination coverage estimates in Table 3 ranged from –3.5 to 6.6 percentage points (median 0.4, 25th percentile –1.4, 75th percentile 1.4). No trends were detected in vaccination coverage estimates for adults or children (pH1N1 or seasonal) by five-level weeks since release (data not shown).

Table 3. Influenza Vaccination Coverage through May 2010 for Early vs. Later & Reweighted Early vs. All Responders, by Vaccine & Selected Respondent Characteristics, National 2009 H1N1 Flu Survey (standalone component)

VACCINE & POPULATION GROUP	Early Responders	Later Responders	Early – Later	Early Reweighted	All	Early Rewt. – All
pH1N1, Children	41.7 (±2.4)	39.9 (±3.5)	1.8 (±4.2)	41.7 (±2.4)	41.1 (±1.9)	0.6
Race/Ethnicity						
Hispanic	49.6 (±6.7)	47.5 (±9.7)	2.1 (±11.8)	49.5 (±6.8)	48.8 (±5.6)	0.7
Non-Hispanic, Black only	35.0 (±8.1)	20.0 (±7.3)	**15.0*** (±10.9)	34.9 (±8.1)	29.7 (±5.9)	5.2
Non-Hispanic, White only	40.8 (±2.6)	40.6 (±4.0)	0.2 (±4.8)	40.9 (±2.6)	40.8 (±2.2)	0.1
Non-Hispanic, other	41.8 (±6.8)	48.9 (±11.8)	–7.1 (±13.6)	41.8 (±6.7)	44.0 (±6.0)	–2.2
pH1N1, Adults	24.4 (±1.1)	23.1 (±1.8)	1.5 (±2.1)	24.3 (±1.1)	24.1 (±0.9)	0.2
Race/Ethnicity						
Hispanic	19.6 (±4.2)	22.9 (±7.1)	–3.3 (±8.3)	19.7 (±4.4)	20.7 (±3.7)	–1.0
Non-Hispanic, Black only	16.8 (±3.1)	15.8 (±3.9)	1.0 (±5.0)	16.8 (±3.1)	16.5 (±2.4)	0.3
Non-Hispanic, White only	26.7 (±1.1)	24.2 (±1.8)	**2.6*** (±2.1)	26.7 (±1.1)	26.1 (±1.0)	0.6
Non-Hispanic, other	23.0 (±4.7)	27.8 (±6.8)	–0.8 (±8.2)	23.0 (±4.6)	24.3 (±3.8)	–1.3
Age Group (years)						
18–24	19.8 (±3.1)	19.3 (±4.3)	0.5 (±5.3)	19.7 (±2.5)	19.8 (±3.1)	–0.1
25–29	20.0 (±3.5)	22.4 (±6.7)	–2.4 (±7.6)	20.8 (±3.2)	20.1 (±3.5)	0.7
30–34	22.0 (±3.3)	23.2 (±5.6)	–1.2 (±6.5)	22.4 (±2.8)	21.9 (±3.3)	0.5
35–44	23.8 (±2.6)	19.1 (±3.2)	**4.7*** (±4.1)	22.3 (±2.0)	23.7 (±2.6)	–1.4
45–49	26.7 (±5.3)	24.7 (±7.4)	2.0 (±9.1)	26.1 (±4.3)	26.8 (±5.5)	–0.7
50–54	23.1 (±3.1)	19.8 (±3.9)	3.3 (±5.0)	22.1 (±2.4)	23.0 (±3.1)	–0.9
55–64	28.6 (±2.3)	29.1 (±3.8)	–0.5 (±4.4)	28.7 (±2.0)	28.6 (±2.3)	0.1
≥65	27.7 (±2.0)	27.9 (±5.7)	–0.2 (±6.0)	27.9 (±2.1)	27.7 (±2.0)	0.2
pH1N1 Target Group						
Not in target group	20.1 (±1.1)	20.0 (±2.3)	0.1 (±2.5)	19.9 (±1.2)	20.0 (±1.0)	–0.1
In target group	30.5 (±2.0)	27.3 (±2.9)	3.2 (±3.5)	30.4 (±2.1)	29.6 (±1.7)	0.8
Health Care Setting (HCS)						
Does not work in HCS	22.1 (±1.1)	21.0 (±2.0)	1.1 (±2.2)	22.0 (±1.1)	21.9 (±0.9)	0.1
Works in HCS	45.8 (±4.9)	41.1 (±5.4)	4.8 (±7.3)	45.8 (±5.1)	44.4 (±3.7)	1.4
Seasonal, Children	45.6 (±2.3)	45.9 (±3.6)	–0.3 (±4.2)	45.6 (±2.3)	45.7 (±1.9)	–0.1
Race/Ethnicity						
Hispanic	51.5 (±7.5)	41.5 (±10.0)	10.0 (±12.5)	51.6 (±7.6)	48.4 (±6.0)	3.2
Non-Hispanic, Black only	39.3 (±8.0)	45.8 (±10.8)	–6.5 (±13.4)	39.2 (±8.0)	41.3 (±6.2)	–2.1
Non-Hispanic, White only	44.4 (±2.2)	45.6 (±3.7)	–1.3 (±4.3)	44.4 (±2.2)	44.7 (±1.9)	–0.3
Non-Hispanic, other	51.9 (±6.8)	59.0 (±11.3)	–7.1 (±13.2)	52.0 (±6.8)	54.0 (±5.9)	–2.0
Seasonal, Adults	43.3 (±1.0)	41.8 (±1.9)	1.5 (±2.1)	42.8 (±1.1)	43.0 (± 0.9)	–0.2
Race/Ethnicity						
Hispanic	28.1 (±3.5)	35.4 (±6.1)	**–7.3*** (±7.0)	27.9 (±3.4)	30.3 (±3.1)	–2.4
Non-Hispanic, Black only	36.4 (±3.8)	32.6 (±5.3)	3.8 (±6.6)	35.9 (±3.8)	35.1 (±3.1)	0.8
Non-Hispanic, White only	47.8 (±1.1)	45.1 (±2.0)	**2.7*** (±2.3)	47.4 (±1.1)	47.1 (±1.0)	0.3
Non-Hispanic, other	38.8 (±4.2)	44.8 (±7.2)	–6.1 (±8.3)	38.5 (±4.2)	40.4 (±3.6)	–1.9
Age Group (years)						
18–24	24.5 (±3.1)	28.7 (±5.5)	–4.2 (±6.3)	24.4 (±3.1)	25.7 (±2.7)	–1.3
25–29	27.5 (±3.7)	30.3 (±6.1)	–2.8 (±7.1)	27.3 (±3.7)	28.3 (±3.2)	–1.0
30–34	35.1 (±3.8)	31.4 (±5.6)	3.6 (±6.8)	34.9 (±3.8)	34.0 (±3.1)	0.9
35–44	35.1 (±2.4)	34.6 (±3.7)	0.4 (±4.4)	34.9 (±2.4)	34.9 (±2.0)	0.0
45–49	36.8 (±3.3)	35.0 (±5.4)	1.8 (±6.3)	36.7 (±3.4)	36.4 (±2.8)	0.3
50–54	41.8 (±3.1)	45.3 (±7.4)	–3.5 (±8.0)	41.8 (±3.1)	42.8 (±3.1)	–1.0
55–64	52.9 (±2.3)	55.3 (±3.9)	–2.4 (±4.5)	52.9 (±2.3)	53.5 (±2.0)	–0.6
≥65	72.5 (±2.0)	69.3 (±3.8)	3.2 (±4.3)	72.5 (±2.1)	71.9 (±1.8)	0.6

Table 3, cont'd.

VACCINE & POPULATION GROUP	Early Responders	Later Responders	Early – Later	Early Reweighted	All	Early Rewt. – All
Seasonal, Adults (cont'd)	41.7 (±2.4)	39.9 (±3.5)	1.8 (±4.2)	41.7 (±2.4)	41.1 (±1.9)	0.6
Seasonal Target Group						
Not in target group	25.0 (±1.6)	28.4 (±2.8)	**–3.4*** (±3.3)	24.9 (±1.6)	26.0 (±1.4)	–1.1
In target group	53.2 (±1.3)	50.6 (±2.3)	2.6 (±2.7)	52.7 (±1.3)	52.6 (±1.1)	0.1
Health Care Setting (HCS)						
Does not work in HCS	41.1 (±1.1)	39.6 (±2.0)	1.5 (±2.3)	40.5 (±1.1)	40.8 (±1.0)	–0.3
Works in HCS	62.0 (±3.2)	60.0 (±5.6)	2.1 (±6.4)	61.7 (±3.2)	61.5 (±2.8)	0.2

* Statistically significant difference in estimated vaccination coverage between early and later respondents, $p < 0.05$.

DISCUSSION

This study found moderate differences in many sociodemographic and other characteristics between early and later cooperators to a telephone survey about influenza vaccination. For key influenza-related opinions and vaccination status, some differences were found between early and later responders. After restricting the sample to early responders and adjusting the weights by poststratification to population control totals, these differences were reduced. With 77% of the total respondents classified as early respondents, differences between early and later respondents would need to be larger to result in substantial bias from restriction of the sample to early respondents. Assuming later responders were representative of nonresponders, nonresponse bias of influenza vaccination coverage estimates from the full sample were estimated to be less than two percentage points for the majority of population subgroups examined.

Similar to a previous study using the 2004 Behavioral Risk Factor Surveillance System, this study found early cooperators were more likely to be older, non-Hispanic White, and female (Biemer & Link, 2008). That study reported a larger difference (7.6 percentage points) in receipt of influenza vaccination between early and later cooperators (defined by number of call attempts) but similarly found a smaller difference (2.6) between early cooperators and all respondents.

This study is among the first to evaluate early responders from a cell phone sample. Fewer differences were found between early and later responders to the cell sample compared to the landline sample; in some cases, the opposite effect was found. In the cell sample, early responders were more likely to be younger and male, and race/ethnicity was not associated with responder status. Influenza vaccination coverage did not differ by responder status for the cell sample, but there were differences for two of the opinion outcomes, with an opposite early responder effect between cell and landline samples for one of them. These findings underscore the need for further studies to evaluate factors associated with propensity to respond to cell phone surveys, and implications for nonresponse bias.

The five-week rolling sample design of the NHFS maximized response rates while allowing weekly estimates during the 2009–2010 influenza pandemic. For the 2010–2011 season, the CDC needed estimates for the start of National Influenza Vaccination Week (NIVW) in early December. Because the incidence of influenza vaccination typically changes substantially during October and November, a short survey field period was desired to provide the most up-to-date estimates with results available in time for use during NIVW. Thus, the 2010–11 season National Flu Survey was conducted November 1–13, 2011. The findings of this NHFS analysis suggest that estimates would not have been substantively different with a longer field period. Future two-week rapid influenza surveys should consider including a subsample followed for a longer time to allow assessment of early responder bias, which may differ in different influenza seasons depending on the nature of public perceptions and saliency related to severity of influenza season, shortage

of vaccine, or safety issues. For repeated cross-section designs like the NHFS, cost could have been reduced by about 13% if restricted to two-week rolling panels; these resources could be redirected to increasing sample size.

This report has several limitations. If the NHFS had been designed with a two-week follow-up period, survey operations likely would have been modified, as was done for November 1–13, 2010, National Flu Survey, which would tend to improve the results compared to restricting to early respondents in a longer period survey. While reducing the field period appeared not to affect results, the bias in estimates based on the full sample is unknown. The nonresponse bias analysis assumed that later respondents were representative of nonrespondents, which may not be true. Thus, further studies comparing NHFS results to external sources are needed to assess overall bias. Because the NHFS was conducted for the purpose of monitoring influenza vaccination during a pandemic, response propensity may have been influenced by topic saliency and altered the early cooperator effects as compared to other general purpose surveys conducted at the same time or in future inter-pandemic influenza seasons.

When timely information is needed for decision making during emergency situations, tradeoffs may be necessary with other survey attributes (e.g., response rates). The "fitness for use" of survey estimates in this situation will depend on how the estimates will be used (Groves et al., 2009), how much potential random and systematic error can be tolerated, and the loss function associated with incorrect conclusions resulting from survey error. This study indicates that shortening the field period of a telephone-based influenza vaccination survey can provide more rapid results without increasing systematic error.

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Does Using Multiple Modes Increase Sample Representativeness?

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Designed Missingness to Better Estimate Efficacy of Behavioral Studies

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INTRODUCTION

Randomized trials of diverse behavioral interventions routinely observe declines in problem behavior among **control** subjects that cannot be attributed to flawed experimental design (e.g., contamination). For example, in nearly a dozen separate studies of risky drinking among adults reviewed by the U.S. Preventive Services Task Force, the average decline in drinking from baseline to follow-up among treatment subjects was 28%, but was 16% for control subjects (Whitlock, Polen, Green, Orleans, & Klein, 2004). Explanations for this pattern of effects generally focus on *assessment reactivity*, which refers to changes in behavior that result from exposure to either intensive assessment protocols used to identify subjects for inclusion in the research study or routine baseline research assessments in a pretest-posttest control group design (Jenkins, McAlaney, & McCambridge, 2009). In other words, the research activities and procedures themselves may constitute an intervention of sorts, and control subjects in this context may be better characterized as an "intervention lite" group as opposed to an untreated control group. Such conditions may lead to serious underestimates of the efficacy of behavioral interventions. An additional complication with long baseline assessments is incomplete data.

One possible remedy for this problem is the use of "designed missingness" in the collection of baseline or pretest data. This strategy, which intentionally collects data on only a subset of cases and/or indicators and uses imputation techniques to address the resulting structured missingness, has been employed to increase the efficiency and cost-effectiveness of data collection in large-scale epidemiologic studies (Strauss et al., 2010). In the current study, we employed a designed missingness strategy for a different objective: to mitigate the potential for assessment reactivity. The following sections present our motivating example for this study, the methods we used, the results, and finally, a discussion.

MOTIVATING EXAMPLE

This strategy was implemented as part of the Connecticut Youth Suicide Prevention Initiative conducted from 2006–2009 by the Connecticut Department of Mental Health and Addiction Services and the University of Connecticut Health Center. Seventeen (CT) schools were included in the intervention, which featured the "Signs of Suicide" (SOS) prevention program, a brief school-based suicide prevention program produced by Screening for Mental Health, Inc. The study utilized a randomized pretest-posttest experimental design, with outcomes assessed at baseline and at three months post-intervention using anonymous questionnaires administered during class. Four versions of the pretest questionnaire were used: one full version and three truncated versions, each of which included a different subset of items in the full version. Three out of sixteen technical high schools were randomly selected to receive one of three truncated versions of the pretest questionnaire. In addition, class periods in a separate large comprehensive high school were randomly selected to receive one the four versions of the questionnaire. Table 1 specifies the questions asked of students on each of the four pretests. The truncated versions were modified to reduce the amount of behavioral information collected at baseline among control subjects.

The SOS instrument measures students' attitudes and knowledge about suicide. Attitudes were measured with a ten-item scale, and knowledge with a 7-item scale (Aseltine & DeMartino, 2004). The initial survey had 1,586 cases, but 295 cases were not used due to a missing VERSION on the questionnaire. Thus, the final sample size for this study is 1,291 students. The sample was 58% male and 42% female. Ten percent of respondents spoke English as a second language. The students self-identified their race/ethnicity as White non-Hispanic (60%), Black non-Hispanic (6%), Hispanic (23%), multi-ethnic (9%), and other (2%).

Table 1. Questionnaire Items, by Version

Item	Versions				Content	Valid Values
Q1	0	1			People who talk about suicide don't really kill themselves.	Yes/No (1/5)
Q2	0	1			People who commit suicide are usually suffering from depression or some other mental illness.	Yes/No (1/5)
Q3	0			3	Most suicide attempts occur without any warning signs or clues.	Yes/No (1/5)
Q4	0	1			Depression is an illness that doctors can treat.	Yes/No (1/5)
Q5	0			3	The best thing to tell a suicidal friend is to "pull yourself together and things will get better."	Yes/No (1/5)
Q6	0		2		If I talk to someone about their suicidal feelings, it may cause them to commit suicide.	Yes/No (1/5)
Q7	0		2		Alcohol use is not related to suicidal behavior.	Yes/No (1/5)
Q8	0		2		Sometimes young people have so many personal problems they have no other options besides suicide.	Likert (1/2/3/4/5)
Q9	0	1			If someone really wants to kill himself/herself, there is not much anyone can do about it.	Likert (1/2/3/4/5)
Q10	0		2		It's none of my business if a friend says he/she wants to kill himself/herself.	Likert (1/2/3/4/5)
Q11	0		2		If I were feeling really down, I would try to talk to a counselor or some other adult about my problems.	Likert (1/2/3/4/5)
Q12A	0	1		3	If a friend told me...: I wouldn't know what to do.	Likert (1/2/3/4/5)
Q12B	0	1		3	If a friend told me...: I would keep it to myself.	Likert (1/2/3/4/5)
Q12C	0		2	3	If a friend told me...: I would wish that I had not found out about it.	Likert (1/2/3/4/5)
Q12D	0			3	If a friend told me...: I would keep it a secret if my friend made me promise not to tell.	Likert (1/2/3/4/5)
Q12E	0			3	If a friend told me...: I would tell an adult at school about it.	Likert (1/2/3/4/5)
Q12F	0			3	If a friend told me ...: I would tell a parent or some other adult outside of school about it.	Likert (1/2/3/4/5)

MULTIPLE IMPUTATION

Multiple imputation (MI) is a technique initially proposed by Rubin (1977, 1978). The basic procedure of multiple imputation is quite simple. We create *m* multiple complete data sets, filling in the missing observations in a principled way. The objective of MI is to use complete-data methods to analyze a data set. Multiple imputation incorporates the uncertainty due to the missing data in the imputation process (Harel & Zhou, 2007). We perform a complete-data analysis on the *m* different data sets and then combine the results using rules defined by Rubin (1987). A good summary of multiple imputation as well as software is provided by Harel and Zhou (2007).

Multiple imputation combines aspects of both the Bayesian and frequentist statistical paradigms. The imputed data sets are often created using Markov Chain Monte Carlo (MCMC) simulations. However, the complete-data analysis often uses frequentist statistical methods. This research implements the multiple imputation methodology of Raghunathan and colleagues (2001), which is well suited to survey data where there are many different variable types and the data structure can be complicated by skip patterns.

Imputations are obtained by fitting a sequence of regression models and drawing values from the corresponding predictive distributions. The types of regression models used are linear, logistic, Poisson, generalized logit, or a mixture of these depending on the type of variable being imputed. The method also allows the imputations to be restricted to relevant subpopulations or to satisfy bounds on the variables.

Software to implement the method is available as a SAS macro called *IVEware*. This macro produces imputed values for each individual in the data set conditional on all the values observed for that individual (Raghunathan, Solengerger, & Van Hoewyk, 2002). Imputation is done on a variable-by-variable basis while conditioning on all observed variables. Imputations are created using a sequence of multiple regressions, varying the type of regression model by the type of variable being imputed. Covariates include all other variables observed or imputed for that individual. The imputations are drawn from the posterior predictive distribution specified by the regression model with a flat or non-informative prior distribution for the parameters in the regression model. Variables are imputed in sequence, each time overwriting previously drawn values. This builds in dependencies among imputed values and uses the correlation structure among the covariates. To generate multiple imputations, the same procedure can be applied with different random starting seeds or taking every p^{th} imputed set of values in the cycles mentioned above. This research uses 100 multiple imputations based on a recommendation in Harel (2007). We analyze the influence of test version on survey response for both the complete data and using multiple imputation.

RESULTS

The attrition and completion rates by version are summarized in Table 2. Cases are complete if

- **Version 0:** a respondent responded to all of the nondemographic questionnaire items (Q1–Q28)
- **Version 1:** a respondent responded to all of the questionnaire items for Version 0 ***except*** Q3, Q5, Q6, Q7, Q8, Q10, Q11, Q12C, Q12D, Q12E, and Q12F
- **Version 2:** a respondent responded to all of the questionnaire items ***except*** Q1, Q2, Q3, Q4, Q5, Q9, Q12A, Q12B, Q12D, Q12E, and Q12F.
- **Version 3:** a respondent responded to all of the questionnaire items ***except*** Q1, Q2, Q4, Q6, Q7, Q8, Q9, Q10, and Q11.

Cases are considered "attritions" if respondents did not even attempt the questionnaire; they are incomplete if it was attempted but some questions were left blank. As indicated by the contrast between and completion rates for version 0 versus all other versions, we found that the response rate was larger for the truncated versions of the questionnaire compared to the full version.

There was also a significant effect of the use of "designed missingness" on individuals' response patterns at pretest and posttest. In particular, we examined the effect of version on attitudes toward and knowledge of suicide in the pretest, the posttest, and in the difference between the two. We regressed each question on version, controlling for race, gender, reduced lunch status (Lunch), grade point average (GPA), and mother's education level (MomEd):

$$Q_i = \beta_0 + \beta_1 \text{Version} + \beta_2 \text{Race} + \beta_3 \text{Gender} + \beta_4 \text{Lunch} + \beta_5 \text{GPA} + \beta_6 \text{MomEd}$$

We present both complete case analysis and multiple imputation. The regression coefficients for VERSION along with their p-values for each item are given in Table 3. As the data in Table 3 indicate, out of 17 questions, six had a significant version coefficient. All version coefficients indicated that students who

answered the question at pretest had more knowledge or more favorable attitudes toward suicide in the posttest.

In addition to regressions for each individual item, we computed a summary statistic for the attitude questionnaire items. The SOS Average variable (SOSavg) is an overall measure of student attitudes about suicide. It consists of the average score of all or a subset of questionnaire items Q8–Q12F. Pretest version 0 subjects received all 10 questions, while subjects of the other pretest versions received a subset of those questions (see Table for details). Each of these questions is a Likert-scale question with five possible responses. A higher SOS Average score represents more negative responses with regard to suicide attitudes. Questionnaire items Q11, Q12E, and Q12F needed to have their responses reversed to match the scales of the other items. We compute SOSaverage for each respondent, and present the mean SOSaverage for the pretest and posttest of controls compared with the truncated versions. Figure 1 shows the mean SOS average of controls compared with the truncated versions.

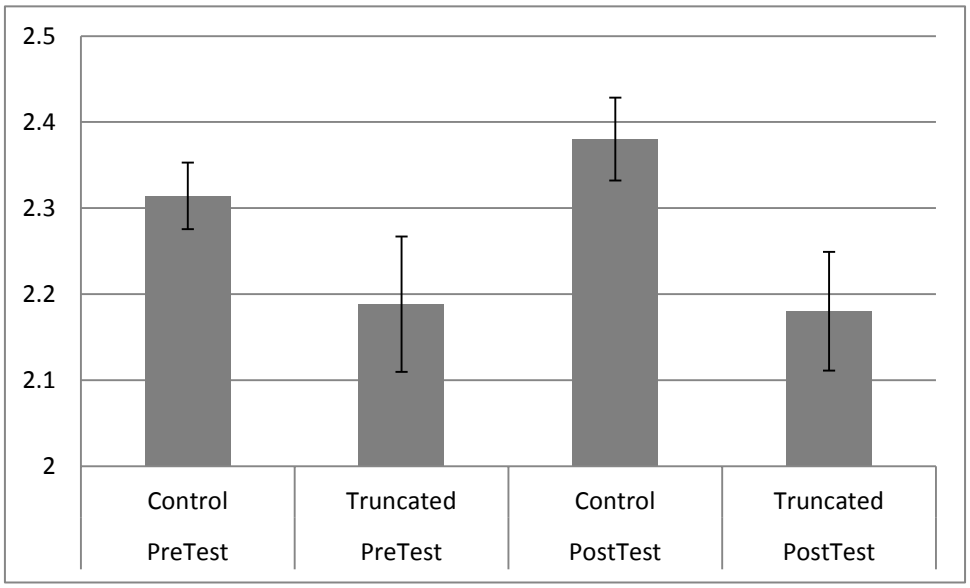
Table 2. Attrition & Completion Rates, by Version

Test	*n*	Demographic Variables?	Version	Attrition Rate	Completion Rate
Pretest	1,291	Yes	All	4/1291 = 0.0031	984/1291 = 0.7622
	982	Yes	0	4/982 = 0.0041	720/982 = 0.7332
	114	Yes	1	0	99/114 = 0.8684
	117	Yes	2	0	101/117 = 0.8632
	78	Yes	3	0	64/78 = 0.8205
Posttest	1,291	Yes	All	237/1291 = 0.1836	818/1291 = 0.6336
	982	Yes	0	212/982 = 0.2159	577/982 = 0.5876
	114	Yes	1	7/114 = 0.0614	89/114 = 0.7807
	117	Yes	2	16/117 = 0.1368	89/117 = 0.7607
	78	Yes	3	2/78 = 0.0256	63/78 = 0.8077

Table 3. Significance of Version in Regressions

Item	Questionnaire Versions	Posttest Complete	Posttest MI	Result
Q1	0, 1	NS	NS	
Q2	0, 1	NS	NS	
Q3	0, 3	0.5512 (0.0089)	0.5317 (0.0125)	More knowledge
Q4	0, 1	–0.5182 (0.0080)	–0.5734 (0.0031)	More knowledge
Q5	0, 3	NS	NS	
Q6	0, 2	0.4566 (0.0403)	0.4929 (0.0242)	More knowledge
Q7	0, 2	–0.3980 (0.0646)	NS	Less knowledge
Q8	0, 2	NS	NS	
Q9	0, 1	–0.3425 (0.0415)	–0.4996 (0.0019)	Better attitude
Q10	0, 2	NS	NS	
Q11	0, 2	NS	NS	
Q12A	0, 1, 3	NS	–0.3293 (0.0910)	Better attitude
Q12B	0, 1, 3	NS	–0.4218 (0.0304)	Better attitude
Q12C	0, 2, 3	NS	NS	
Q12D	0, 3	NS	NS	
Q12E	0, 3	NS	NS	
Q12F	0, 3	0.3311 (0.0381)	NS	Better attitude

Figure 1. Mean SOS for Controls Compared with Truncated Versions



The data in Figure 1 show that the multiple imputation mean SOS differs by version. The three groups receiving truncated versions of the pretest questionnaire remained relatively stable in their pretest and posttest attitudes, while those completing the full version at pretest improved (significantly) in their attitudes (e.g., had more adaptive attitudes) from pretest to posttest.

There were two main findings of this study. First, the completion rate for the truncated versions was around 85% while the completion rate for the nontruncated version was 73% in pretest, and the posttest completion rate was 59% for the nontruncated version compared to 78% for the truncated versions. It is important to note that the posttest questionnaire was the same for all versions and only the pretest questionnaire was truncated. Second, after imputations, treatment effects were significantly larger for subjects who were assigned the truncated versions of the pretest than for subjects who were assigned the nontruncated questionnaire at pretest.

DISCUSSION

The objective of this pilot study was to test the hypothesis that pretest questionnaires may affect responses to the posttest questionnaire, hence affecting the magnitude of treatment effects. We found that truncated pretest questionnaires increased questionnaire completion rates and provided stronger tests of treatment effects. Although more research is needed on this subject to establish optimal questionnaire configurations and study designs, "designed missingness" methods have the potential to improve the assessment of treatment effects in a broad range of efficacy studies.

The response rate (posttest) was significantly larger for the truncated (pretest) versions (8%) compared to the full version (22%). There are differences in patterns of responses to questions on the posttest depending on whether respondents got a particular question on the pretest. The pattern of responses based on getting a particular question at pretest is very interesting. For six of the seven items, those who got the question at pretest were significantly more likely to have more accurate knowledge about depression/suicide and better attitudes in terms of how to deal with it. This suggests that there is some learning happening as a result of exposure to the pretest, which is one of the things that concerns us when we have to "test" people prior to an intervention to assess its effects.

The (pretest) testing itself can produce posttest changes in the outcome measures irrespective of effects of the intervention. It was beneficial to use multiple imputation to reduce assessment reactivity. After imputations, treatment effects were significantly larger for subjects who were assigned the truncated versions of the pretest than for subjects who were assigned the non-truncated questionnaire at pretest.

The objective of this pilot study was to test the hypothesis that pretest questionnaires may affect responses to the posttest questionnaire, hence affecting the magnitude of treatment effects. Although more research is needed on this subject to establish optimal questionnaire configurations and study designs, "designed missingness" methods have the potential to improve the assessment of treatment effects in a broad range of efficacy studies.

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Correction for Survey Nonresponse and Measurement Error

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NONRESPONSE & MEASUREMENT ERROR

Surveys often employ adjustments that aim to correct for nonresponse. Such adjustments typically increase the variance of estimates, invoking a tradeoff between bias reduction and variance inflation.

Corrections for measurement error in public use data files are seldom—if ever—made. Yet, depending on the influences on nonresponse in a survey and the factors affecting misreporting to a particular question in that survey, bias in an estimate can be dominated by measurement error. Several studies already have demonstrated instances where measurement is the dominant source of bias compared to nonresponse (Groves & Magilavy, 1984; Olson, 2006). Thus, corrections for measurement error in addition to adjustments for nonresponse are needed. Moreover, these corrections need to be accessible to the wide range of data users rather than to a select few who could implement complex procedures to estimate the combined effect of multiple error sources (e.g., Biemer, 2001; Jackman, 1999; Voogt, 2005).

There could be common causes and correlates for nonresponse and measurement error (e.g., Peytchev, Peytcheva, & Groves, 2010). If, for instance, interviewers with particular characteristics or skills lead to less nonresponse *and* lower measurement error, interviewer selection criteria and training can be altered to reduce total survey error. Conversely, experienced interviewers have been found to achieve higher response rates but elicit lower reporting of sensitive behaviors suggesting that a greater proportion of experienced interviewers could yield less nonresponse in a survey, but higher measurement error (Chromy et al. 2005). Such information would be useful in correcting for both sources of error.

The relative magnitude of each error also needs to be measured in order to help reduce total survey error in an estimate. Steps could be taken to embed design features for the reduction of the dominant source—thus disproportionately allocating study resources where they make the greatest impact. For example, finding that most of the error stems from underreporting to interviewers, a greater number of questions can be included in the self-administered portion despite the possibly higher nonresponse if the instrument is lengthened. The magnitude of each error has similar implications for postsurvey adjustments. The largest source of error should receive greater attention in modeling efforts, and collection of more auxiliary information to inform these models. For example, if underreporting of a sensitive behavior is the dominant source of bias in population prevalence estimates for this behavior, correlates of how sensitive the respondent finds this topic and how likely she is to report it to an interviewer could be most beneficial (in addition to correlates of the behavior itself).

This leads to two related research questions that can be posed for a given estimate:

1. Are there common correlates of nonresponse and measurement error?
2. What are the relative magnitudes of nonresponse and measurement error?

To answer each of these questions, however, methods are needed to estimate each source of error. This is the focus of the next section.

MULTIPLE IMPUTATION FOR UNIT NONRESPONSE, ITEM NONRESPONSE, & MEASUREMENT ERROR

Rather than weight for nonresponse and omit adjustments for measurement error, we propose implementing multiple imputation for both sources of error, treating both as missing data problems. Multiple imputation involves the filling of missing values in variables using a selected imputation method and repeating the process multiple times, creating multiple datasets. Imputed values vary across the datasets to the extent that there is uncertainty in the imputation. Variance is estimated by adding the variance of the estimates of the parameter of interest, say a proportion, between the multiple imputed datasets (between imputation variance) and the average variance of the estimate across the datasets (within imputation variance). For a detailed discussion, the reader is referred to the seminal work by Rubin (1978; 1987); a less technical presentation can be found in the IVEware manual (www.isr.umich.edu/src/smp/ive/). Analogous to weighting, multiple imputation is not by itself a method but an approach. Different methods of imputation can be used within the multiple imputation inferential framework. However, it is most often associated with methods that model each variable rather than the nonresponse mechanism. For the present study, an increasingly common and widely available method was selected—sequential regression multiple imputation (Raghunathan et al., 2001)—and described in more detail in the next section.

There are several important theoretical and practical advantages to using multiple imputation instead of weighting for unit nonresponse, three of which are of critical importance to the reduction of survey errors. First, imputation can model the variable of interest rather than on whether a sample member responded to the survey. That is, the imputation models typically address the problem of how sample members would have responded if they had completed the interview. In contrast, weighting for nonresponse addresses the question of how likely these sample members were to respond to the survey. Even when both models fit reasonably well, the difference between these two objectives can lead to greater variance in survey estimates that employ weighting, compared to imputation, particularly when the identified mechanisms producing unit nonresponse are not strongly associated with the survey variables. Thus, weighting typically *increases* variance estimates, especially when the response propensity model is highly predictive of nonresponse (Little & Vartivarian, 2005). A good-fitting imputation model, however, can potentially lead to *lower* variance estimates.

Second, model specification in imputation can be variable-specific, while in weighting the same weights are used for all or majority of survey variables. Rather than limiting which auxiliary variables can be used for an overall adjustment, imputation methods such as those employing regression can tailor the set of auxiliary variables and model specification to each specific survey variable, such as including different higher order interactions that would vary across models—thus producing better adjustments for each survey variable. Thus, imputation could not only lead to lower variance estimates but also lower bias, compared to weighting.

Third, imputation allows for the use of a larger array of auxiliary variables by easily incorporating data subjected to missingness themselves. When weighting is employed, either only variables without missing data are used or variables with low levels of missingness are used after imputation. In contrast, multiple imputation as a method initially conceived for dealing with item nonresponse (Rubin, 1987) readily incorporates variables with missingness even when it is substantial. For example, administrative data may be highly associated with survey variables but available only for a relatively small proportion of the sample; multiple imputation can incorporate such data to help further reduce nonresponse bias and can also account for the uncertainty in the missing values of the auxiliary variables.

Multiple imputation also can be used for measurement error by treating it as a missing data problem—when the information with more desirable measurement properties is not available for part or even the entire sample. Several studies have attempted multiple imputation for measurement error, whether through simulation, a validation study to a larger survey, a survey with physical measures of only part of the sample, or simply a survey deemed less measurement error-prone compared to administrative data, making an argument for the benefits of this approach to reduction of measurement error (Brownstone & Valletta, 1996; Cole, Chu, & Greenland, 2006; Ghosh-Dastidar & Schafer, 2003; Raghunathan, 2006; Yucel & Zaslavsky, 2005).

This leads to a third important research question:

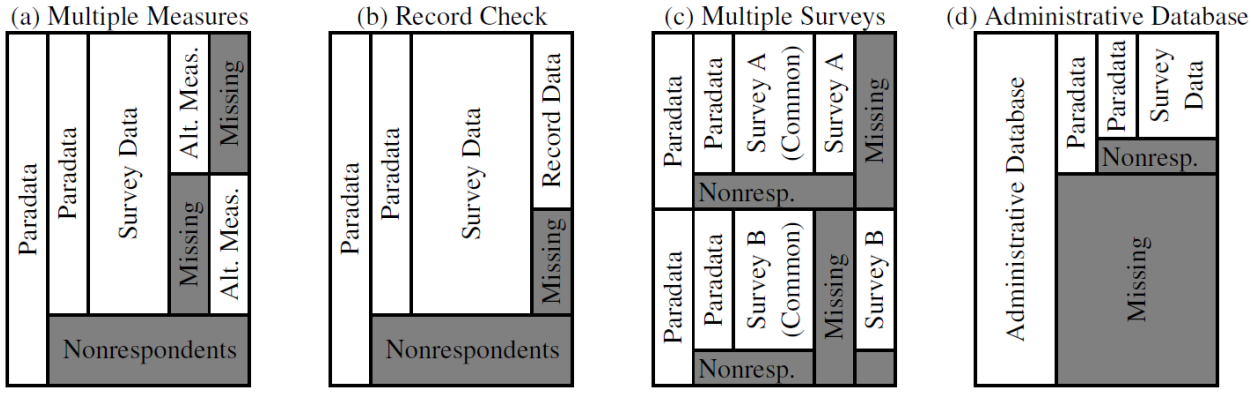
3. Could multiple imputation for unit nonresponse, item nonresponse, and measurement error reduce standard errors and total survey error (MSE) for an estimate, compared to weighting?

This question is one that may have the broadest implications and may spur future research, as it addresses the inherent need to address both nonresponse and measurement error effectively and efficiently in surveys. A necessary discussion at this point needs to be about the circumstances in which multiple imputation for nonresponse and measurement error can be particularly relevant.

TYPES OF DATA STRUCTURES FACILITATING MULTIPLE IMPUTATION FOR NONRESPONSE & MEASUREMENT ERROR

Several general designs can be identified in which both nonresponse and measurement error in household surveys could be addressed through multiple imputation—we briefly describe four. A first type of design is when a superior approach to the collection of accurate survey reports is available but not feasible to collect for the entire sample. For example, the National Survey of Family Growth (NSFG) collects information on sensitive behaviors, such as abortion experiences, that are subjected to underreporting when asked by an interviewer. Underreporting due to the social interaction between the interviewer and the respondent can be minimized by asking about such behaviors in a self-administered portion of the interview. To control the length of the self-administered part of interview and respondent engagement, either a small number of questions can be re-asked in the self-administered part of the interview or different respondents can be asked subsets of the sensitive questions, again creating a missing data problem in the less measurement error-prone reports. Furthermore, some respondents may refuse to answer some or all of the self-administered questions. Another example of this data structure is the National Survey of Drug Use and Health (NSDUH), which uses field interviewers to collect mental health data, among other measures. Serious mental illness is identified based on these data. Improved measurement can be achieved through administration of multiple mental health scales by clinical researchers. Use of highly trained professionals and a separate data collection is costly and can only be afforded for a small subsample of NSDUH respondents, creating a missing data problem in the improved measures that were handled through weighting (Aldworth et al., 2010). The resulting missing data pattern is presented in Figure 1 (panel a), which we label the Multiple Measures design. To fill in all the shaded areas, as well as any item nonresponse in any of the data, multiple imputation can be employed.

Figure 1. Four General Types of Data Structures That Pose the Need for Both Nonresponse & Measurement Error Correction



Another general design is when external validation data may be obtainable, but only for part of the respondents, shown in Figure 1 (panel b). For example, the National Election Studies (NES), conducted for the last six decades in the U.S., are subjected to social desirability in reports of voting behavior, resulting in overreporting. Voter validation was conducted in several election years in which attempts were made to verify whether the respondent actually voted. Since validation is not possible for the entire sample for a number of reasons (e.g., moving, problems in matching, and local laws) this creates a missing data problem that should lend itself to imputation—multiply imputing voter validation data for the entire pool of survey respondents. This is not a rare paradigm—several ongoing national health surveys collect record data after interviewing respondents, such as immunization records (the National Immunization Survey, NIS) and medical expenditures (the Medical Expenditure Panel Survey, MEPS).

A third design is when data may come from multiple surveys, each survey offering less measurement error for different sets of concepts. The utility of the data collected by each survey is then increased, by having a greater number of respondents and greater array of survey measures. Some surveys currently combine their data but only to achieve a greater number of interviews for analyses—variables that are not collected on one of the surveys are left missing. One ambitious project to combine data across surveys is the Collaborative Psychiatric Epidemiology Surveys, bringing together data from the National Comorbidity Survey Replication (NCS-R), the National Survey of American Life (NSAL), and the National Latino and Asian American Study (NLAAS). This project has allowed for much more in-depth analyses that would otherwise be limited by sample size. Imputation, however, could also allow analysis of the combined data using variables deemed to have least measurement error.

The fourth design is in some respects the converse of the record check design. In some instances the sampling frame is an administrative database. In fact, sometimes the key information is already available in the administrative database. However, the administrative data may be seen as flawed by measurement error and the goal of conducting the survey is to collect more accurate data. For example, Statistics Norway conducts surveys to obtain more accurate estimates of income, although tax data are readily available to the agency from the national register. Thus, collecting more accurate measures for a sample of the target population as well as collecting variables that help explain the discrepancies between the administrative and survey data and the more accurate data can be imputed for everyone who was not selected for the survey.

Next, we present an application of multiple imputation for nonresponse and measurement error in a study that falls in the first general design. We use it to obtain relative magnitudes of each source of error and to compare it to weighting.

DATA AND METHODS

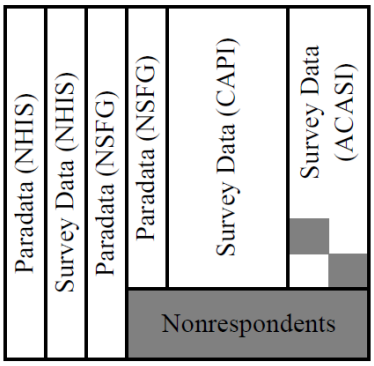
The NSFG cycle 5, conducted in 1995, presents a unique opportunity to gain insight into the common correlates of nonresponse and measurement error and to compare the magnitudes of each error. The sampling frame for the NSFG was the 1993 NHIS respondent pool, which achieved a household respondent response rate of 95.6%. Women and girls who were 12–44 years old by 1995 were eligible; 14,000 were selected for NSFG, of which 13,795 were eligible sample members at the time of interviewing and 10,847 completed interviews. Among the selected respondents from the NHIS, the unweighted and weighted response rate for NSFG were 78.6% and 78.7%, respectively (Potter et al. 1998), providing potential for nonresponse bias. It is nonresponse to NSFG that we call unit nonresponse from here on. This methodology creates a very rich sampling frame for the NSFG with numerous types of information on both respondents and nonrespondents, and most notably, includes health related variables that can be particularly useful in measuring and adjusting for nonresponse bias in NSFG.

Key to NSFG are estimates of abortion experiences. These sensitive behavior reports, however, are subjected to measurement error when asked by interviewers. The prevalence of abortion based on survey reports has been found to be underestimated compared to other sources (Fu et al. 1998; Jones and Forrest 1992; Smith, Adler, and Tschann 1999). The most common explanation for this underestimation is that females who have experienced an abortion are subjected to social stigma in reporting it to an interviewer. Indeed, removing the social interaction of the personal interview has been found to lead to higher reports of having ever had an abortion (Lessler, Weeks, and O'Reilly 1994). Cycle 5 was the first time Audio Computer Assisted Self Interviewing (ACASI) was used to obtain these estimates (in addition to the questions asked by the interviewer), which method has been found to lead to higher reporting of socially undesirable behaviors (Tourangeau and Smith 1996). We use these data to define an estimate of measurement error as any woman who reported having had an abortion in ACASI but reported no abortions to an interviewer in the Computer Assisted Personal Interviewing (CAPI) section.

There may be common causes of nonresponse and measurement error. For example, one may hypothesize that an older interviewer can achieve higher response rates and less nonresponse bias because sample members find it more difficult to refuse to her, while she may be also more likely to evoke greater underreporting of abortion experiences if perceived as more socially undesirable compared to a younger interviewer. Common causes, however, may not be necessarily found in the NSFG cycle 5. The relative magnitudes of nonresponse bias and measurement error bias, nonetheless, are of great importance to the optimization of survey design. If, for example, bias in estimates of lifetime abortion experiences is dominated by nonresponse, and measurement error does not lead to substantively important differences, resources should be directed to the reduction of nonresponse bias; and vice versa. To address this question, we first need to estimate nonresponse and measurement error bias in this estimate.

Five sets of ancillary data can help inform both sources of error, presented in Figure 2: sample member characteristics from NHIS, survey data from NHIS, paradata from NHIS, and two types of paradata from NSFG—interviewer beliefs, experiences, and characteristics and respondent self-reports gauging the likelihood of measurement error.

Figure 2. Missing Data Structure in NSFG



In addition to the major missing data patterns in NSFG cycle 5 presented in Figure 2, all observed data including survey and paradata are subjected to item nonresponse, creating a "Swiss cheese" missing data pattern. A *sequential regression multiple imputation* approach is well suited for such missing data problems where values for variables with least missing data are imputed first in order to inform imputation of variables with more missing data, then iterating through perturbations so that imputed values for the first variable are also informed by the variable with a higher proportion of missing data. The process is repeated multiple times, allowing the incorporation of the imputation uncertainty in the survey estimates (Rubin 1978; Rubin 1987). The sequential regression multiple imputation was carried out in IVEware (Raghunathan et al. 2001). Analysis was conducted using IVEware and SUDAAN 10 (Research Triangle Institute, 2008). For each analysis, 25 multiply-imputed data sets were created. In addition to entering all variables used in the analysis as main effects in the imputation models, interactions were included between interviewer and respondent race, Hispanic origin, and age.

To identify common correlates of nonresponse, nonresponse bias, and measurement error, four logistic regression models were estimated. All models employed the complex sample design variables and the survey weights. The survey weights that were constructed for this analysis were the product of the NSFG selection weights and the final NHIS weights that include adjustments for nonresponse to NHIS. As noted, missing values in predictor variables were multiply imputed and used across the different error models. The first two models focused on nonresponse and nonresponse bias. Model 1 regressed whether the sample member was a nonrespondent on demographic characteristics, NHIS survey responses, NHIS paradata, and NSFG interviewer beliefs, experiences, and characteristics.

For any of these variables to be related to nonresponse bias, they have to be associated with both nonresponse and the survey variable. Model 2 relates the same set of predictors to the potential for nonresponse bias in unadjusted estimates by regressing the CAPI abortion reports on these predictors.

The third and fourth models were directed at measurement error. Model 3 regressed the estimated measurement error, defined as not reporting an abortion in CAPI ($y = 0$) among those who reported having had an abortion in ACASI, also on the same set of independent variables. A common correlate of nonresponse and measurement error would have a similar and significant coefficient in Model 3 as in Model 1. Additionally, common causes or correlates of nonresponse *bias* and measurement error would have significant coefficients in Model 1, 2, and 3.

Finally, Model 4 is an attempt to improve the measurement error model by using measures collected only from respondents. Underreporting was regressed on a larger set of predictors to include respondent self reports related to measurement error in CAPI responses to sensitive questions.

The entire set of predictors was used in two ways: to create imputed datasets with no missing data (except for logical restrictions) and nonresponse adjusted weights. Imputation was implemented using IVEware as described earlier, using all the covariates in Model 4. Missing values for having ever had an abortion were imputed for both CAPI and ACASI. Measurement error, defined as CAPI reports among those who reported an abortion in ACASI, was recomputed. The weighting approach involved estimation of response propensities, employing the same variables to focus the comparison to multiple imputation on the analytic approach, rather than the variables used. In order to avoid confounding the comparison between multiple imputation and weighting with how item nonresponse in the abortion variable is treated (i.e., typically ignored in weight construction and cases dropped in analysis), the weighting approach also included adjustments for item nonresponse in CAPI and ACASI reports of abortion.

RESULTS

Among the 2,189 women who reported an abortion in ACASI, 397 (18.1% unweighted, or 18.5% when weighted using the combined NHIS final weights and NSFG base weights) reported not having had an abortion to the interviewer in the CAPI part of the interview. Contrary to previous findings, measurement error was *not* associated with nonresponse. The selection-weighted differences among those who reported an abortion in ACASI in underreporting across quintiles formed by response propensities were not significant, with 18.6%, 19.0%, 17.4%, 18.1%, and 19.3%, in the lowest through highest propensity quintile, respectively ($\chi^2(4) = 0.358$), $p = 0.986$). Similarly, the mean response propensity was not different for those who reported an abortion in ACASI compared those who did not, 0.778 and 0.780, respectively ($F(1,88.9) = 0.084$), $p = 0.773$).

A common cause or correlate of nonresponse and measurement error, a variable needs to be significant in models 1, 2, and 3. There were no such covariates. Most parameter estimates were significant in either one of the nonresponse or measurement error models, with age, race, and Hispanic origin being an exception, presented in Table 1.

These findings suggest that each error source can be treated separately, to improve abortion reports in this study design. The determination on which error source to focus can be informed by the relative magnitude of each error—the second main research question in this study. To address it, three estimates were compared: (1) using CAPI reports from respondents weighted only for selection probability, thus subjected to both unit nonresponse and measurement error, (2) using CAPI reports from respondents and imputed CAPI reports for all eligible nonrespondents, addressing unit nonresponse, and (3) using ACASI reports from respondents and imputed ACASI values for nonrespondents, addressing both nonresponse and measurement error.

Table 2 shows that nonresponse accounted for only 1.41 percentage point bias in the abortion estimate (16.09% vs. 17.50%). However, measurement error accounted for an additional 3.84% bias, with an estimate of 21.34% based on the full sample ACASI imputed data. The pattern was the same for the estimates using weighting.

The third research objective is to empirically evaluate whether the multiple imputation approach could yield efficiency gains over propensity score weighting. Despite the use of *multiple* imputation that accounts for the uncertainty in imputed values, imputation led to estimates with smaller standard errors than the complete case analysis, shown in the first three data rows in Table 2. Weighting, however, led to a loss in efficiency due to weight variation. While imputation led to a substantial *decrease* in the standard error of the CAPI estimate by almost 50% (from 0.83% to 0.43%), weighting led to an *increase* of more than 50% (to

1.29%). This is consistent with the theoretical justification (e.g., Little & Vartivarian, 2005) and is the first empirical demonstration in a national household survey to show such results.

Table 1. Logistic Regression Models Predicting Nonresponse, Potential for Nonresponse Bias, & Measurement Error Propensity

		NONRESPONSE ERROR				MEASUREMENT ERROR			
		Model 1: Nonrespondent in NSFG		Model 2: Reported Abortion in CAPI		Model 3: Underreported in CAPI		Model 4: Underreported (Expanded Model)	
VARIABLE	CATEGORY/UNIT	*Beta*	*(S.E.)*	*Beta*	*(S.E.)*	*Beta*	*(S.E.)*	*Beta*	*(S.E.)*
Demographic Characteristics (NHIS)									
Any unrelated individual in household	Yes	0.142	(0.087)	–0.106	(0.135)	–0.153	(0.240)	–0.207	(0.247)
Birth region	Midwest	–0.473***	(0.115)	–0.069	(0.106)	0.128	(0.235)	0.165	(0.245)
	Northeast	–0.363***	(0.096)	–0.063	(0.106)	0.290	(0.242)	0.185	(0.262)
	South	–0.341**	(0.117)	–0.198	(0.106)	0.216	(0.258)	0.231	(0.257)
	West	–0.652***	(0.114)	–0.040	(0.105)	0.114	(0.404)	0.156	(0.432)
	Mexico	–0.227	(0.241)	–0.069	(0.219)	0.475	(0.713)	0.559	(0.723)
Geographic location	1,000,000 or more	0.370**	(0.120)	–0.026	(0.099)	0.059	(0.263)	0.054	(0.266)
	250,000–999,999	0.210	(0.120)	–0.036	(0.102)	0.170	(0.252)	0.200	(0.267)
	100,000–249,999	–0.003	(0.144)	0.079	(0.162)	0.179	(0.272)	0.200	(0.303)
	Under 100,000	–0.078	(0.191)	–0.042	(0.229)	0.937**	(0.317)	0.681	(0.364)
	Non-MSA-Other Urban Areas	–0.221*	(0.102)	–0.043	(0.128)	–0.186	(0.344)	–0.027	(0.354)
Hispanic origin	Yes	–0.363*	(0.156)	–0.022	(0.117)	–0.106	(0.267)	–0.155	(0.255)
Race	White	–0.274**	(0.089)	0.027	(0.125)	–0.179	(0.235)	–0.308	(0.211)
	Black	–0.311***	(0.094)	-0.019	(0.184)	–0.281	(0.211)	–0.465*	(0.234)
Marital status	Married	–0.008	(0.080)	–0.180*	(0.091)	–0.088	(0.232)	–0.096	(0.219)
	Separated, divorced, or widowed	0.011	(0.092)	0.041	(0.116)	0.092	(0.235)	0.163	(0.237)
More than high school	Yes	–0.221***	(0.051)	–0.063	(0.067)	0.024	(0.140)	0.086	(0.141)
Family income	Under $10,000	0.048	(0.117)	–0.196	(0.137)	0.307	(0.249)	0.337	(0.268)
	10,000–19,999	0.184	(0.098)	–0.070	(0.099)	0.290	(0.239)	0.370	(0.261)
	20,000–34,999	0.013	(0.074)	–0.075	(0.105)	0.275	(0.185)	0.277	(0.203)
	35,000–49,999	–0.094	(0.091)	0.088	(0.089)	0.037	(0.233)	0.063	(0.251)
Age	Years	0.017***	(0.004)	0.005	(0.005)	–0.001	(0.009)	–0.006	(0.010)
Health-Related Variables (NHIS)									
Height	Inches	0.002	(0.009)	–0.019	(0.012)	0.006	(0.028)	0.008	(0.027)
Weight	Pounds	–0.004***	(0.001)	0.000	(0.001)	0.000	(0.002)	0.001	(0.002)
Family size	People	–0.049**	(0.019)	–0.007	(0.020)	–0.014	(0.037)	–0.037	(0.043)
Health status	Excellent	–0.139	(0.084)	0.189	(0.142)	–0.521*	(0.225)	-0.437	(0.267)
	Very good	–0.118	(0.090)	0.192	(0.148)	–0.508*	(0.200)	–0.455*	(0.221)
	Good	–0.163	(0.098)	0.216	(0.132)	–0.526**	(0.193)	–0.593**	(0.211)
Activity limitation status	Unable to perform major activity	0.200	(0.158)	0.282	(0.235)	–0.987*	(0.463)	–1.078*	(0.482)
	Limited kind/amount major activity	0.184	(0.125)	0.311*	(0.152)	–0.075	(0.262)	–0.009	(0.276)
	Limited in other activities	–0.035	(0.143)	–0.078	(0.169)	0.286	(0.363)	0.304	(0.375)
Restricted activity days in past 2 years	Days	0.004	(0.009)	0.011	(0.016)	–0.016	(0.024)	–0.024	(0.030)
# doctor's visits in past 12 months	Visits	–0.009	(0.005)	–0.004	(0.003)	0.008	(0.009)	0.011	(0.009)
# bed days in past 12 months	Days	0.001	(0.002)	–0.002	(0.001)	–0.001	(0.004)	0.000	(0.004)

Table 1, cont'd.

VARIABLE	CATEGORY/UNIT	NONRESPONSE ERROR Model 1: Nonrespondent in NSFG Beta	(S.E.)	NONRESPONSE ERROR Model 2: Reported Abortion in CAPI Beta	(S.E.)	MEASUREMENT ERROR Model 3: Underreported in CAPI Beta	(S.E.)	MEASUREMENT ERROR Model 4: Underreported (Expanded Model) Beta	(S.E.)
Paradata (NHIS)									
Telephone	Yes, given	–0.372**	(0.118)	–0.194	(0.110)	0.366	(0.267)	0.397	(0.272)
	Yes, not given	0.565***	(0.165)	–0.269	(0.180)	0.218	(0.415)	0.435	(0.511)
Respondent type	Self-entirely	–0.270***	(0.061)	0.101	(0.068)	–0.237	(0.151)	–0.270	(0.167)
	Self-partly	–0.077	(0.100)	0.026	(0.105)	0.024	(0.324)	0.048	(0.331)
Paradata—Interviewer Beliefs, Experiences, & Characteristics (NSFG)									
First time interviewer	Yes	–0.025	(0.118)	0.022	(0.155)	0.129	(0.226)	0.065	(0.242)
Interviewer with more than high school	Yes	–0.358**	(0.126)	0.051	(0.083)	0.078	(0.182)	0.112	(0.190)
Interviewer of Spanish/ Hispanic descent	Yes	–0.080	(0.173)	–0.049	(0.127)	–0.304	(0.286)	–0.368	(0.286)
Interviewer race	White	0.053	(0.262)	0.101	(0.203)	–0.094	(0.408)	–0.149	(0.446)
	Black	–0.022	(0.261)	0.177	(0.199)	–0.108	(0.417)	–0.159	(0.462)
Interviewer marital status	Married	0.194	(0.179)	0.121	(0.201)	0.412	(0.283)	0.452	(0.299)
	Separated, divorced, widowed	0.009	(0.199)	0.100	(0.176)	0.589	(0.311)	0.709*	(0.333)
Interviewer ever pregnant	Yes	–0.065	(0.173)	–0.058	(0.175)	–0.458	(0.307)	–0.447	(0.312)
Interviewer importance of religion in life	Very important	–0.401***	(0.120)	0.039	(0.103)	–0.006	(0.205)	0.004	(0.213)
	Somewhat important	–0.474***	(0.113)	0.048	(0.091)	–0.057	(0.219)	0.015	(0.232)
Interviewer age	Years	–0.005	(0.005)	0.000	(0.003)	–0.007	(0.006)	–0.009	(0.007)
Paradata—Measurement Error Related to Self-Reports (NSFG)									
People give more honest answer to…	The interviewer							0.334	(0.293)
	Audio self-administration							0.060	(0.175)
Difficulty in using the keyboard	Very easy							–1.376	(27.129)
	Easy							–1.264	(27.109)
	Difficult							–0.775	(27.112)
How did you conduct the self-administered questions?	Read & listened							0.153	(0.123)
	Turned screen off & listened							0.076	(0.388)
Most comfortable answering abortion & # of sexual partners questions	With interviewer							–0.266	(0.320)
	With headphones							1.042***	(0.180)
How likely to give different answers to other questions if self-administered	Very likely							1.541***	(0.205)
	Somewhat likely							0.973***	(0.214)
	Not very likely							0.695**	(0.217)
Intercept		0.725	(0.749)	–0.493	(0.890)	–1.381	(2.038)	–1.481	(27.311)
-2 Log Likelihood (df)		52573034 (33.6)		36766023 (31.4)		7750905 (30.3)		6958223 (29.2)	
Max-rescaled R-square		0.086		0.073		0.074		0.219	
n		13,795		10,664		2,189		2,189	

*$p < .05$, **$p < .01$, ***$p < .001$.

NOTE: Missing data in the predictors were imputed. All models use the same 25 multiple imputations. Reference categories: birth region—other country; geographic location—non-MSA-rural areas; race—other; marital status—never married; family income—$50,000 or more; health status—fair or poor; activity limitation status—not limited (includes unknowns); telephone—no; respondent type—proxy; interviewer race—other; interviewer marital status—never married; interviewer importance of religion in life—not important; people give more honest answer—does not matter; difficulty using the keyboard—very difficult; how did you conduct the self-administered questions—read screen and turned tape off; most comfortable answering abortion and number of sexual partners questions—did not matter; how likely to give different answers to other questions if self-administered—not at all likely.

Table 2. Estimated Percent with Abortion Experiences, Standard Error, & Mean Square Error Based on CAPI Data from NSFG Respondents, Correcting for Nonresponse & for Measurement Error through Multiple Imputation, Weighting, & Use of ACASI Reports

ERROR CORRECTION METHOD	% with Abortion Experiences	Standard Error	MSE Using Weighted Estimate as Truth	MSE Using Imputed Estimate as Truth
Multiple Imputation				
Respondents only (CAPI)	16.09%	(0.83)	37.41	28.25
Imputed for NR (CAPI)	17.50%	(0.45)	21.83	14.95
Imputed for NR and ME (ACASI)	21.34%	(0.48)	0.89	0.23
Weighting				
Respondents only (CAPI)	16.09%	(0.83)	37.41	28.25
Weighted for unit and item NR (CAPI)	17.72%	(1.29)	21.29	14.77
Weighted for unit and item NR (ACASI)	22.15%	(1.74)	3.03	3.68

Since the estimated proportions are almost identical, both about one-third higher than the estimates unadjusted for nonresponse and measurement error and each well-within the confidence interval of the other, the substantially smaller variance estimates in the imputation approach also means lower mean squared error (MSE) compared to weighting. Even if the estimate based on weighting is used as truth in the computation of MSE, the estimate of MSE presented in Table 2 is 3.4 times larger in the weighting approach (3.03/.89). If the estimate based on multiple imputation is used, the estimate of MSE is an astounding 16 times larger in the weighting approach (3.68/.23).

CONCLUSIONS

At a time of declining response rates and rising survey costs, it is imperative to be more frugal about the available data on sample members by exploiting these data as much as possible to understand survey errors, measure them, and correct for them—even when the auxiliary data are subjected to missingness. Of critical importance is to use correction methods that reduce bias, but do not unduly increase variances. Such methods would increase the utility of survey data and provide the means to collect less data to achieve the same survey goals, reducing costs and respondent burden. This study found that multiple imputation can achieve these goals while addressing both nonresponse and measurement error.

To the student of survey error, these findings alert to the dependency of errors and their interplay on the survey design and survey environment. The relationship between nonresponse and measurement error found for abortion reports in NSFG cycle 6 was not found in NSFG cycle 5. The two studies, however, were conducted about seven years apart by different survey organizations, and using different sampling designs, and implementing different data collection procedures. Not only are theories needed to identify common causes of nonresponse and measurement error, but better understanding of the interplay between these causes and survey design characteristics is needed.

Survey practitioners may take some consolation that despite several common correlates of unit nonresponse and measurement error, the two error sources were not related for abortion reports. This allows the practitioner to focus on individual sources of error without being overly concerned about unanticipated impact on the other source of error—in this particular survey design.

An important finding for survey practitioners from this study is the relative magnitude of measurement error bias compared to nonresponse bias. Arguably, nonresponse bias estimates are routinely computed in surveys but parallel estimates of measurement error bias are seldom attempted. As a result, resources may

be disproportionately allocated towards the reduction of nonresponse bias although the dominant source of error for a particular estimate or set of estimates may be measurement error. The sensitive nature of abortion experiences suggests that this may be one such example. Indeed, the computed bias due to nonresponse was a tenth of a percentage point, yet the bias from measurement error was over three percentage points.

Designs in anticipation of multiple sources of error can lend themselves to more effective postsurvey adjustments. A key goal in this study was to demonstrate the ability to use multiple imputation to address unit nonresponse, item nonresponse, and measurement error. Apart from being able to deal with all three of these sources of error simultaneously, multiple imputation can achieve lower variance estimates than the commonly used single weight adjustment that focuses on the interview outcome. In fact, in this study, multiple imputation not only yielded lower variance estimates compared to those under weighting, but also lower variance estimates compared to complete case analysis—not a loss, but a *gain* in efficiency or a design effect of less than one.

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SESSION 3 DISCUSSION

Charles DiSogra (Knowledge Networks)

What do we mean by "optimization"? It is fairly obvious that we want to make the most with what we have, squeezing more out of the methods and data at hand, and more to the point, economizing our health survey efforts. We have five papers on this theme, but before I raise some discussion points, I have a second task to accomplish today.

WEB PANELS

The session's organizers asked me to raise another related issue. The many papers submitted on optimizing health surveys covered a number of survey modes, but it was most disappointing that there were so few papers, in this age of the Internet, using Web-based data collection. So, to borrow from an old marketing slogan, "Where's the beef?" we ask, where's the Web?

Although one paper in this session is grounded in Web-based data collection, certainly there is much more health-related research out there using Web-based panels for the sample and Web as the collection mode. I think sessions such as today's need to see and discuss the types of Web-based studies and methods currently being used. We need an updated dialog about Web surveys and especially Web panels as to what viable role they can play in health survey methods today and into the near future.

All survey methods have their limitations as well as their advantages; this is also true when it comes to Web panels and their accuracy (Yeager et al., 2009). In the spirit of full disclosure, my current employment with Knowledge Networks does bias me in my opinions about aspects of the large volunteer opt-in panels. But, as a methodologist, I want to review some opportunities that may exist in using these volunteer opt-in panels and, of course, in using probability-based panels such as Knowledge Networks' KnowledgePanel®.

These opt-in panels are large online volunteer panels with membership sizes in the millions. Anyone on the Web can join them by responding to recruitment advertisements or pop-up invitations or by going to recruitment Web sites that aggregate multiple panels, giving you a chance to join as many as you like (based on topic interest and usually opportunity to earn cash incentives). There is also blanket e-mail marketing to recruit panel members. Not all opt-in panels are equal; some work harder at achieving recommended industry standards for tenure, eliminating "professional respondents," controlling for member overlap among panels, and general panel management. Industry organizations, such as the Advertising Research Foundation, work to set voluntary standards for online panels. These panels are used extensively by market researchers with the advantages of being low cost, having a rapid data turnaround, delivering large sample sizes, and locating target audiences using profile data already collected on panel members. They can pull quick quota-like or purposive samples using a variety of proprietary techniques and can even weight samples, again using proprietary methods. But, if you just want the raw data, that's good, too.

In 2009, the market research industry spent about $2 billion on online research. According to *Inside Research* (2009) and quoted in the *AAPOR Report on Online Panels* (Opt-In Online Panel Task Force, 2010), "about 85% of that research replaces research that previously would have been done with traditional methods, principally by telephone or face-to-face." So, what are some of the methodological limitations? Basically, these opt-in Web panels are convenience samples. They are not probability-based samples drawn from any definable frame. If anything, members come from among people on the Web and obviously with Web access. Their findings are not generalizable for prevalence estimates, even though some researchers do

it anyway. The methods used by these opt-in panel firms are not always transparent. Generally, their survey completion rates are quite low, and because they are not probability samples from a known frame, true response rates cannot be calculated (Callegaro & DiSogra, 2008).

On the plus side, these opt-in panels do have some state-of-the-art Web-based programmed questionnaire administration that can display video, motion graphics, and other animation and play sound. They also will deliver a clean data file and do all this relatively quickly and at a low cost. These can be very attractive features for the right purpose. But can they be used for health research? Yes, but only with great caution and probably only for some kinds of research. Some examples might be for concept testing, examining relationships between variables, methods testing for Web survey development, missingness studies, reaching a fairly good sample size of some rare groups or persons with rare health conditions (who are on the Web), doing exploratory surveys, and probably other types of studies you can imagine.

However, if you need a representative sample with generalizable results or prevalence estimates in the U.S. population with valid confidence intervals on those estimates, then you want a probability-based panel like KnowledgePanel. This panel's members are recruited from national samples drawn from the U.S. Postal Service's computerized delivery sequence file. This is an address-based frame inclusive of some 97% of the physical addresses in the entire U.S. In this way, every sample unit has a known probability of selection and thus the descriptor of being a probability-based sample. Address-based sampling, or ABS, means that telephone status becomes irrelevant since participants are recruited based on mailing address using printed materials. Cell phone, cell mostly, landline, and no phone all are included. Since people are being recruited to join an online Web panel, households without Internet access are provided with a laptop computer and free monthly ISP service as long as they remain on the panel. This is the unique Knowledge Networks solution in addition to offering this panel membership and survey participation in Spanish as well as English. (Note that the Hispanic members of KnowledgePanel are called KnowledgePanel Latino^{SM}, as they are also a representative panel for U.S. Latinos.)

One point I want to make here is that you can report true response rates for studies done with a probability-based sample. However, you need to appreciate a new paradigm for panel response rates. These rates are a multiplicative function consisting of a recruitment rate, a profile rate (i.e., providing the essential background information to obtain panel membership), and the survey sample's completion rate (see Callegaro & DiSogra, 2008). So don't be surprised when this math produces a low double-digit or even single-digit response rate. This is actually a perfect example of having a high-quality survey with an apparent low response rate, but such low-number response rates need to be recognized as the normal domain of what are, in fact, high-quality probability-based panel studies.

An alternative to KnowledgePanel is to build one's own probability-based panel. What should be better known is that Knowledge Networks uses its experience, staff skills, and engineering infrastructure to help universities and other groups build custom Web panels for their research use and purposes.

Finally, a hybrid method that been used successfully with a number of health and other studies calibrates an opt-in panel sample with a probability-based sample. This approach uses paradata to minimize any bias introduced from the opt-in cases in a final weighted sample blended from these two sources. You would do this when the finite size of the probability-based panel is unable to deliver the desired sample sizes for a given study. Although many health-related studies using calibrated samples have been done at Knowledge Networks, where are they at this conference? This is certainly a viable optimization method that needs more exposure and discussion.

THIS SESSION'S PAPERS

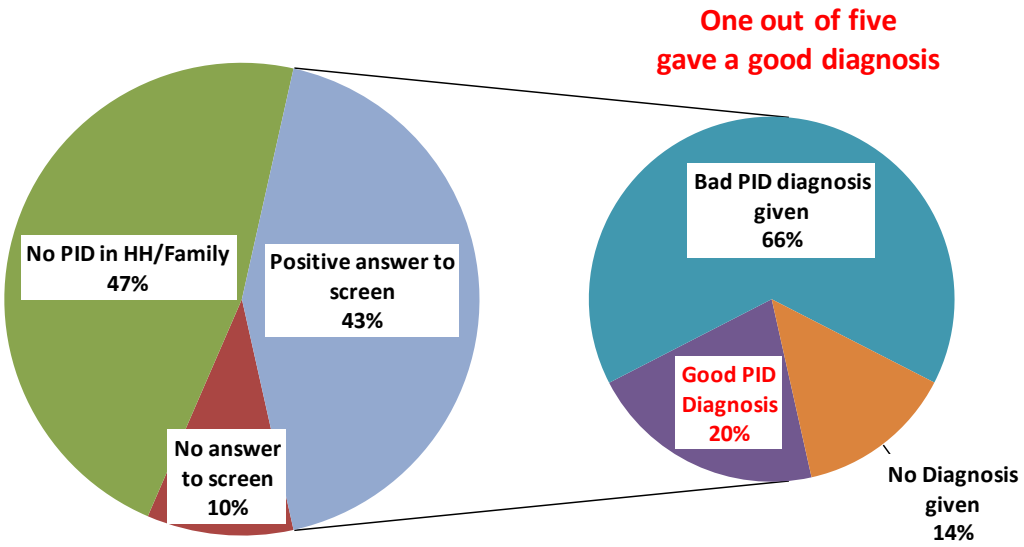
Five studies were presented, each optimizing some element of five different survey types. One employed a mega opt-in Web panel to locate patients with a rare disease. This is what I call thinking out of the box, since a true prevalence study using a probability-based sample approach would be cost-prohibitive for this team. In an effort to locate and interview at least 120 cases, this was a most practical idea. A second paper looked hard at whether or not a short time period, rapidly fielded telephone survey can out of necessity produce "good enough" information for urgent monitoring purposes. The third paper explored whether or not telephone follow-up calls, when you can reach people by telephone, biases findings from a mail survey. Although proper weighting should effectively mitigate this type of bias. At least, I believe, that's the point of doing weighting. Our fourth paper used paper and pencil questionnaires in a classroom setting, but employed planned missingness to reduce respondent burden and at the same time demonstrating an intriguing Hawthorne effect-like phenomenon in its control group (Gillespie, 1991). And finally, our fifth paper tackled the issue of nonresponse and measurement error using multiple imputation techniques applied to traditional in-person data collection. With a wide array of variables from two large surveys of which one is a subset of another plus paradata from interviewers about themselves and the interview experience, this study is what you might call a "variable perfect storm" all coming together!

As survey scientists, when we look at the optimization efforts in these papers, the errors of our ways become more transparent. And, not all errors are necessarily bad. When John Boyle sees opportunity in nonprobability Web panels, knowing they are not a representative sample, that's both bold and resourceful. Jim Singleton takes a step back and sees the pragmatic opportunity to use early responders as a bellwether, knowing that a likely bias could be tolerated in his application. Jeanette Ziegenfuss re-examines the use of telephone follow-up efforts in a mail survey as a potential mixed mode problem that researchers may be ignoring. Ofer Harel takes up the challenge of incorporating planned missingness in a survey questionnaire design and absorbs the higher analyst burden to do so. And finally, Andy Peytchev immerses his work in the disentanglement of measurement and nonresponse errors using elaborate multiple imputation models, a kind of multiple imputation gone wild, so to speak. All of this done in pursuit of minimizing bias measured with mean square error. I kind of think of this minimalization endeavor as "taming of the skew," if you will excuse this pun.

WEB PANELS AND RARE DISEASES

One thing to pay attention to when working with a large opt-in Web panel is the usually low completion rates associated with their invitations to get panel members to take a survey. This is just the invitation, not the survey itself. As reported in this first paper, only 13% accepted the invitation to take the survey. Although there were almost 900,000 persons on this panel that was attempting to identify patients with a rare immune deficiency disease, effectively the researches had the attention of "only" about 115,000 of them. Still, this is a lot of people. But nonresponse is not ignorable. Unsurprisingly, only 3% of these reported a qualifying "rare" immune problem, but less than half of these 3,486 "found" cases completed the eligibility screener resulting in the identification of just 144 eligible cases. That's some significant nonresponse along the way. However, what this study did exceptionally well was to have a very tight and exhaustive set of screener questions to maximize assurance of eligibility. I think this is essential when working with opt-in Web panels since we can't ignore the fact that some panel members may not be totally truthful or attentive. Of those who advanced to take the screener, only 43% were identified as potentially eligible with a desired immune disease diagnosis. Note that 10% did not give any answers to the screener for unknown reasons.

Figure 1. This figure shows that of the 43% who gave a positive answer to the screen, only one out of five gave a good diagnosis making them eligible for the study.



Upon completing the screener, two out of three were eliminated with a bad or erroneous diagnosis, and another 14% could not or did not give a diagnosis (who were they?). Only one out of five gave a good diagnosis making them eligible for the study.

From a what-I-like-to-see perspective when reporting results from Web surveys, it is important to address quality-control procedures such as how questionnaire "speedsters" were identified and handled or how straight-lining and other evidence of inattentive response patterns were dealt with. The study's finding that certainly appears intuitively credible is that the type of treatment patients receive is associated with the setting in which their immunologist practices. If anything, this illustrates that an opt-in Web panel source can reveal notable associations of value to this type of research. One caution I have for the authors is to not conclude that their findings "confirm" but instead say they "suggest" that nonmedical center patients are being undertreated. Given the high level of nonresponse and the source of their data, I think this is a more appropriate wording.

MONITORING H1N1 FLU IMMUNIZATION

This CDC survey work is a dual-frame landline RDD and cell phone sample. When doing these kinds of surveys, it is important to describe how the field administration was handled in the cell phone component. Were all cell-phone persons interviewed or just those who reported living in cell-only households? How was this handled in the weighting of the two combined samples? These are important methodological elements to be made transparent given the rapidly growing proportions of cell-only/mostly households and the resultant impact on telephone surveys. The paper did not address these issues.

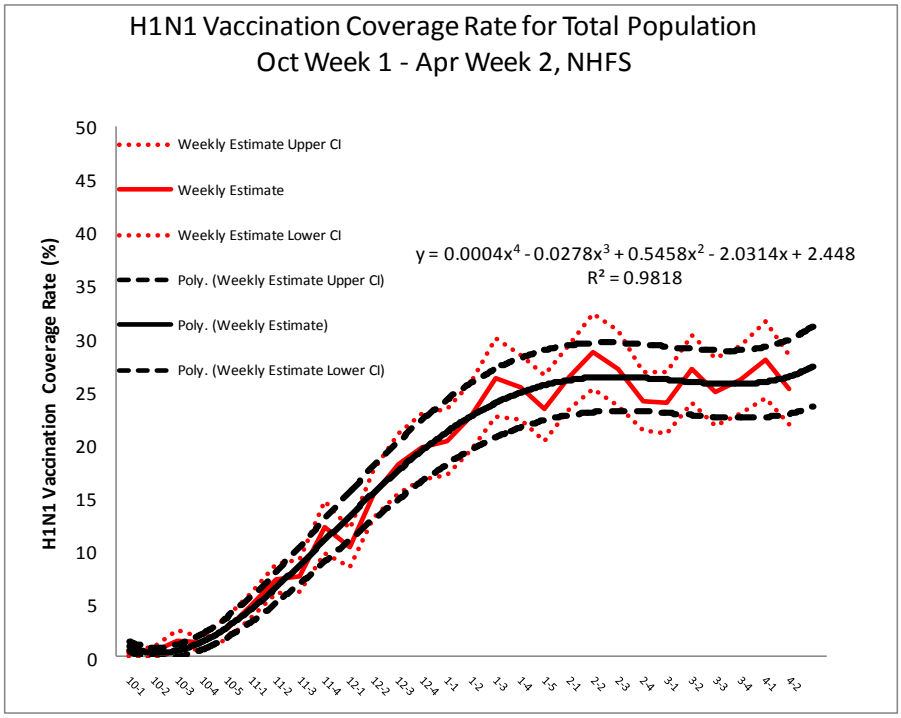
It was no surprise that the early responder landlines were more likely White, older, and retired, while early responder cell phones tended to be younger, Hispanic, and employed. This encapsulates the descriptive picture of each of these communication device populations based on what we know from the National Health Interview Survey (NHIS) data on wireless and landline populations (Blumberg & Luke, 2010). Another methodological weakness and likely a confounder in obtaining an accurate prevalence estimate is respondent recall, especially among late responders. Survey participants are asked to report on

their vaccination status for the week the survey is fielded. Some three to five weeks after the week of interest, there has to be some recall issues clouding the information provided by late responders.

While the authors conclude that a two-week rapid survey may be sufficient for urgent monitoring purposes, data collected from an additional three weeks of "late responder" effort tend to correct the early estimate downward by about two percentage points. If the bulk of resources goes into a rapid two-week survey, some resources might be set aside for a parallel five-week phone survey so a correction factor can be obtained and applied to the weekly prevalence picture retroactively. Thus, the use of such backward adjustments will provide some historical accuracy to the immunization campaign.

Also, the graphing of weekly immunization prevalence, attitude, or intent information based on survey data might use some kind of curve-smoothing technique. In some instances (e.g., when measuring public attitudes over time about intent to be vaccinated), a simple linear trend line can be fitted to the data, avoiding a "rollercoaster" picture difficult to visually read and interpret. As far as tracking immunization prevalence, a cumulative picture logically should increase from week to week. For demonstration purposes, I took the CDC prevalence data reported in this paper and fitted a polynomial curve to them, including the confidence interval values, and plotted this over the more choppy survey estimates. As shown in Figure 2, this gives a more generalized progressive view of immunization prevalence increase over time.

Figure 2. This figure, using the same graphic used in the presentation, shows how a smooth curve fitted over more erratic weekly survey estimates makes the progressive immunization prevalence picture easier to read.



MULTIPLE MODES & SAMPLE REPRESENTATIVENESS

The Ziegenfuss and Beebe paper presents an interesting dilemma: The earlier mail respondent sample looked "better" before telephone (different mode) follow-up efforts reached out to bring in nonresponders.

After achieving a higher response rate in the end, the final sample composition demonstrated more bias. Bias was assessed by linking 97% of the sample to extensive health records information available from the Rochester Epidemiology Project (REP). The uniqueness of this Olmstead County study population is that they have excellent coverage among health care providers to participate in the REP. As a result, the REP covers a good portion of the county population. With such a rich database, the authors admit this may be a heavily surveyed population. Also, the demographic profile of this population is unique in that it is 90% White and less than 3% Hispanic, and the Mayo Clinic and the Olmstead Medical Center are prestigious institutions with wide name and reputation recognition in this county. All of this makes these survey results difficult to generalize outside of this county.

From a methodological perspective, I was surprised that the sample was not restricted to one person per household. This leads to some loss of unit (patient) independence and makes the study subject to within-household cluster effects; it also may confound response if two-patient households are more likely to have both patients respond.

The authors didn't indicate if the materials used in the mailing were message and design tested with different age focus groups or similar qualitative assessment. Did the decisions about print messages and design presentation appeal more to the population that turned out to be overrepresented? I call this a "materiogenic" response effect, where the responders are more likely to be those to whom the materials appeal to and, conversely, the nonresponders are more likely those to whom the materials are just not talking. Might this have shaped the mail response? This can extend to the caller ID that shows up for telephone calls and even the messages left on answering machines, if messages are left. Also, it is not clear whether cell phones were called or even if they knew they had cell phones. If the follow-up was restricted to landline phones, then a different set of nonresponders would be obtained from this limited set of households, and more bias would be expected to result.

Finally, it wasn't clear if proxy respondents were allowed. This would certainly permit more of the sickest/most disabled patients to be included by both mail and telephone. I think proxy interviews need to be a carefully designed part of a patient population survey; otherwise, we end up with a healthier sample as this study suggested, with some identified health conditions.

The classic design of mail, reminder postcard, mail follow-up, and where possible, telephone follow-up, as in the Total Design Method (Dillman, 1978) style, is here to stay with us for a while, and it is expected that responders at each stage will likely be different, especially if there is a mode change. However, standard poststratification weighting remains the usual solution when the weighting dimensions are carefully identified for the study sample.

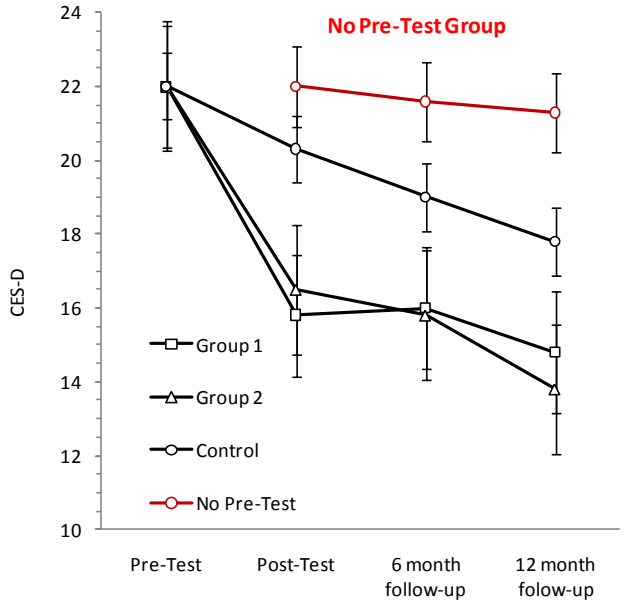
DESIGN MISSINGNESS IN EVALUATION RESEARCH

The theoretical basis for using multiple imputation to address item nonresponse has been known of over two decades (Rubin, 1987). Designing missingness into a survey questionnaire strategy to reduce respondent burden is a clever, proactive statement of faith that results will be meaningful for generalizing from the entire sample. In this piece of evaluation research by Harel et al., we see this application in play. The imputation model covariates are sparse, but this is the choice of the researchers who presumably know the study population and the relevant variables in the sample necessary for imputation modeling. At first I noticed "lunch" as a covariate and assumed there was more here than the presentation of this paper explained (it turned out to be eligibility for participation in the free school lunch program).

While I want to believe that multiple imputation has a valid place in this type of evaluation research, I found the changes in some of the study outcomes after imputation unsettling. The evaluation was measuring the impact of a suicide prevention/education program for teenagers. The multiple imputation data produced a different outcome on four questions. Granted, given the number of questions asked, some will change by chance alone; however, one question (Q12F), to which I would think an educator would pay attention, changed in an undesirable direction. If a teen was told by another teen they were contemplating suicide, would the now-informed teen tell a parent or other adult? The nonimputed data indicates they'd be more likely to do so. With the imputed data, the intervention program had no effect on improving this attitude. That may be due to the fact that the program was truly ineffective on this lesson, or was the imputed data masking the finding? I want to believe the former, but the data set, including the imputed data that produced this finding, still leaves me with some doubt. Which do we believe and on what basis?

I want to address the control group as a baseline against which these changes are being compared. The authors acknowledge they observed "improvement" in the CES-D measures in the control group even though there was no intended educational intervention. They explain a test effect or an assessment reactivity taking place. That is, the process of taking the baseline questionnaire constitutes an "intervention lite" for the control group. This makes it more difficult to assess change in the intervention groups since the control group is changing in the direction that the program would like to produce. I would recommend that the authors on their next design foray consider a quasi-experimental design that eliminates the baseline questionnaire from the control group. As antithetical as that may sound for an experimental design, those familiar with an older text (Cook & Campbell, 1979) will remember such a design to address this very problem. Think of it as an "intervention zero" approach for the control group. Figure 3 illustrates this using a simulation of the data graphic presented in this paper.

Figure 3. This graph, using Center for Epidemiologic Studies—Depression Scale data, illustrates a design where a no-pretest control group receives no baseline measure in order to avoid an assessment reactivity effect. A standard control group with a reactivity effect is also shown.



Simulated data based on a graphic borrowed from:
Mackinnon, A. et al., Br J Psychiatry 2008; 192:130-134

CORRECTING SURVEY NONRESPONSE AND MEASUREMENT ERROR

This last paper by Andy Peytchev is an excellent example of what can be done with access to a wealth of survey variables, especially on nonresponders, to explore both nonresponse and measurement error. Using survey data from the National Survey of Family Growth (NSFG), a subsample of the larger NHIS with a broad array of interviewer paradata available, this research was able to look at a unique sensitive NSFG question on abortion history. The bonus here is that the CAPI question fielded with an interviewer also was fielded with a subsequent verification using an audio-CASI mode to remove interviewer effects and elicit a possibly "more honest" answer. Data from the NHIS were used for nonresponse analyses, and multiple imputation was employed for item nonresponse solutions.

I want to focus on the multiple imputation method since it was reported that imputed data were used to further impute other missing data. This is not entirely unusual, but I am always troubled by the layering of imputed data on imputed data. With this type of "inbreeding" activity where no new data are introduced, it only makes sense to me that the variance around estimates will tend to decrease. Likewise, the mean square error will similarly decrease. Can we honestly claim higher precision in our estimates using the imputed results? I want to believe that the precision we have is never any greater than the extent of the real data that were reported. Would it be more appropriate to report the standard error based on the real data? Should we report both?

I think extensive multiple imputation methods applied to large health surveys, despite the enormous analyst burden it imposes, needs to be evaluated from the perspective of data interpretation and the policy consequences of extracting results and conclusions using multiple imputation techniques with these surveys. I hope this will instigate further discussion on this all-important topic and give the author an opportunity to respond and perhaps, for all of us, an opportunity to reflect.

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SESSION 3 SUMMARY

Mike Battaglia (Abt) and **Martin Barron** (NORC)

OVERVIEW OF THE PRESENTATIONS

Stephen Blumberg introduced the five-paper session by mentioning the CDC concept of winnable public health battles. Examples include increasing seat belt use, reducing smoking, reducing dietary sodium intake, etc. These battles may be carried out through public health campaigns and other approaches. The people leading these initiatives need information from surveys to guide implementation and assess progress. The information is likely to be needed on a quick turnaround basis at the national and/or state level and potentially the substate level. For some public health initiatives, obtaining information quickly and at a low cost per interview may be more important that having highly accurate survey data.

This session looked at techniques such as the use of nonprobability opt-in Internet panel samples, short field period telephone surveys, multimodality mail surveys, and building design missingness in behavioral studies, along with techniques to correct for nonresponse bias and measurement error when a rich set of covariates are available.

John Boyle presented *The Use of Online Panels to Characterize the Management of Rare Diseases: The Case of Primary Immune Deficiency Diseases*. A previous attempt at screening 10,000 households in a national telephone sample yielded only 23 persons with primary immune deficiency diseases (PIDD). National probability samples can do a good job screening for rare populations, but the PIDD population is very rare, making standard probability sampling techniques problematic. One probability sampling method is a multiple frame design that would add list samples to a random-digit-dialing telephone screening sample, but for the PIDD population, no such lists appear to exist. Probability samples make it possible to estimate totals (e.g., the total number of persons in the U.S. with PIDD) and associate a standard error with those totals. This study seemed to be more interested in examining treatment gaps and related associations. The approach of using a nonprobability online panel sample was tested as an alternative to probability sampling. The study used a two-phase screening approach. An invitation was sent to a "balanced sample" of around 880,000 persons in an opt-in Web panel. Those that went to the screener and passed the initial screening questions were invited to go to the questionnaire Web site where a second round of more detailed screening questions were used to narrow the sample down to persons who actually have PIDD. A sample of around 145 persons with PIDD was achieved. This sample found some associations that provided useful information to the Immune Deficiency Foundation. From the point of view of "fit for use," using a nonprobability sample design seemed to work in this specific situation. However, because none of the large federal health surveys collects data on the PIDD population, no benchmarks exist for assessing the accuracy of the estimates of associations found in the opt-in panel sample.

James Singleton presented *Design of Health Surveys for Public Health Emergencies: Early Responder Bias in the National 2009 H1N1 Flu Survey*. The CDC was charged with monitoring the uptake of the H1N1 vaccine from the fall of 2009 through the first half of 2010. Weekly estimates were needed on receipt of the vaccination, intent to vaccinate, and reasons for not seeking to be vaccinated. Primary interest was in cumulative vaccination coverage national and state estimates for high-risk groups such as the elderly and children under age two. The design used a dual-frame telephone sample (landline telephone households and households in a cellular sample that had only cellular telephone service or had cell phones and were not likely to answer the landline telephone in the household). A five-week rolling sample approach with limited

call attempts was used. Each survey week contained early versus late responders in terms of the number of weeks the sample telephone number was in the field. Early respondents were those obtained within the first two weeks of sample release. The concept was to view late responders as a proxy for nonrespondents because the level of effort required to complete an interview was viewed as a continuum of resistance. Each rolling sample was weighted, and the early responders within each rolling sample were reweighted. Although some differences between early and late responders were found for demographic characteristics, when the cumulative proportion vaccinated for the early responders was compared to all responders, the curves pretty much lie on top of each other. It appears that a two-week rolling sample might suffice for rapid data release because the bias in vaccination coverage was no larger than around four percentage points for some subgroups.

Jeanette Ziegenfuss presented *Does Using Multiple Modes Increase Sample Representativeness?* This was an application of sequential multiple modes where administrative (medical records) data were available for most of the population in Olmsted County, Minnesota, to examine nonresponse bias. Multimodality surveys may be used to decrease the cost per completed interview, increase the response rate, and to increase sample representativeness. It is possible that individuals have a mode preference and thus will be more likely to respond if they are offered that mode. This survey used two mailings followed by a telephone survey of mail survey nonrespondents. The overall response rate was 47%, and the second mailing and the telephone survey each added about ten percentage points to the initial response rate. It was possible to compare the respondents to the population on the characteristics available in the medical records. Little evidence of nonresponse bias was found, and the switching of modes from mail to telephone may be more akin to multiple attempt strategies, whereby late responders are brought into the sample but do not differ by a substantial amount on the key survey outcome variables.

Ofer Harel presented *Design Missingness to Better Estimate Efficacy of Behavioral Studies*. This behavioral intervention studied suicide prevention. The population was students in Connecticut schools. It appears that schools were randomized to treatment versus control status, and pre- and postintervention interviews were administered in the schools to the students in the sample. The pretest interview was needed in this randomized design, but it was known that the pretest questionnaire was likely to increase the knowledge and attitudes of students in the control group regarding suicide prevention, which can make the intervention look less effective. Because the pretest was divided into three modules, this could be tested by administering all three modules to some students; for other students, only two of the three modules were administered in a randomized fashion. In effect, this reduces the impact of the pretest questionnaire on the outcomes measured in the posttest interview. The study found that the control group students who received all three modules did exhibit different posttest responses than those who received only two of the modules. In other words, the treatment effect was stronger than a design with no design missingness would have found. Also, students who received only two of the three modules were more likely to participate in the posttest survey than those who answered all three modules at the pretest survey. This type of design missingness approach requires that multiple imputation techniques be used to fill in the missing pretest module data, but this was offered as a design advantage as opposed to a missing data design limitation. This also points out that in a randomized design, if one can avoid the need for a pretest survey, the posttest difference would give an accurate estimate of the treatment effect. This is not always possible because the pretest interview may be used to determine the intervention that will be given to that individual.

Andy Peytchev presented *Correction for Survey Nonresponse and Measurement Error*. Three topics were covered: (1) common causes and correlates of nonresponse and measurement error, (2) magnitude and source of error, and (3) correction approaches. Unit nonresponse can be affected by topic interest, topic

sensitivity, length of interview, interviewer training, etc. With regard to magnitude of survey errors, the survey design should be optimized to address dominant sources of error. As for common correction approaches, nonresponse weighting generally is used—poststratification and propensity weighting. Corrections for measurement error typically are not made. One can use imputation to address missing data due to nonresponse and item nonresponse. This works best if one has a rich set of covariates (from the sampling frame). In weighting, we adjust the weights of the respondents; in imputation, we can impute the Y variables for the nonrespondents and also the missing Y values for item nonresponse among respondents. The idea is to fill in the entire data set. The 1995 NSFG cycle 5 was used to demonstrate this approach. This was a CAPI survey that used the NHIS as a sampling frame. They also have better ACASI measurements for sensitive items (e.g., abortion reporting) within specific replicates. This makes it possible to look at the CAPI estimates prior to imputation, the CAPI estimates after imputation, and the impact of the ACASI measurements on the sensitive items. The multiple imputation approach was compared with a propensity weighting approach. Relative magnitude analysis: (1) 16% abortion estimate before imputation; (2) after imputation for nonresponse, the estimate was 17.5%; and (3) after ACASI adjustment, the estimate rose to 21.3%. The three estimates for weighting versus imputation were similar. But given a rich set of covariates, one may be able to decrease the variance relative to the propensity weighting; the researchers found that SEs were lower for the second and third estimates. In this case, the use of multiple imputation increased complexity for the analyst, but the effective sample size was larger.

Discussant Charles DiSogra indicated that the topic of the session was along the lines of making the most of what you have, squeezing more out of the methods and data at hand, and economizing on effort. For example, opt-in Internet panels are fast and low cost, but many of the panel recruitment, panel maintenance, and estimation techniques are proprietary, and completion rates are very low. Therefore, they may not really be appropriate for prevalence estimates. It was noted that opt-in panels do provide information that allows one to search for and remove responses from "speedsters" and inattentive respondents. This points to a range in quality of nontraditional approaches, and the researcher needs to understand these issues at the design stage so that various quality devices and measures can be built into the implementation of the design.

FLOOR DISCUSSION

Framing of Panel

Much of the discussion focused around whether the content of the discussion should best be framed as "How far are we willing to go to trade quality for cost savings?" or instead as "Is a given method fit for the purpose(s) of a particular study?" But one participant wondered about fitness for use—how is it defined and measured.

According to panel members, some government agencies struggle with the competing demands of cost, quality, and timeliness. While probability sampling is neither impossible nor dead, it is expensive and requires a great deal of effort to gain cooperation. We need to be open to unconventional techniques to address problems that may be unsolvable using traditional methods. The best approach when we think an unconventional approach works is through test and replication.

In addition to the methodologies presented by the panel, audience members suggested a number of alternative designs (e.g., a rolling cross-sectional design or an omnibus survey as an alternative to Web surveys). There also are many people eager to participate in surveys if given the chance. A goal posed by

one commenter is to investigate how we can take advantage of those wishing to participate in a reasonable and structured way.

New Methods

Boyle's Internet panel survey of an extremely rare population was complimented for its rigor, a trait lacking in some other surveys that employ opt-in Internet panels. However, concerns were raised that even high-quality implementations of Internet panels may miss some low-incident populations. Audience members also noted that Internet panels are problematic for looking at trends since the makeup of any given panel can vary substantially from month to month. A key aspect of using this type of nontraditional approach in health survey research is to gain as great an understanding of the detailed working of the methodology as is feasible given the proprietary nature of some of these tools.

In employing new methods, one audience member argued that it can't be done in half steps (e.g., using an Internet panel but still trying to calculate some approximation of a response rate or considering a panel to be an independent frame). Instead, we should be concerned with questions relevant to the method: Are people who they claim to be, are data machine entered, etc.?

Some discussion revolved around whether it is preferable to employ more complex methods that increase the burden on analysts. At least two panel members believed that is the preferred course. For example, a complex public use data file based on the use of multiple imputation greatly increased burden on the analyst, but a well-done data release will provide documentation and even programs on how to take the added complexity into account. Data users must be willing to invest in understanding how to take the increased complexity into account when they analyze the data.

Response Rates

Several audience members discussed the limits on alternative methods placed by clients, journals, and IRBs. One audience member noted that some journals have minimum response rates requirements. Others have clients with requirements or IRBs that place limits on or require certain response rates; unfortunately, some efforts to increase response rates also can increase error. For example, incentives might improve response but reduce the quality of answers a respondent gives.

One alternative is to educate clients, journal editors, and IRBs on the limits of response rates. OHRP has begun to discuss the possibility that surveys could be exempted, but that could only occur if and when certain safeguards were in place (e.g., to ensure data confidentiality).

Education also requires better measures of response error. Multiple factors that contribute to survey error need to be considered.

Imputation

The discussion of the advantages of using imputation to create a complete data set with all survey variables present for both nonrespondents and respondents compared with traditional weighting approaches focused on the variable-specific nature of imputation (i.e., each Y variable is imputed for nonrespondents and respondents with missing values) versus the creation of a single weight for only the respondents. For a single Y variable, if one used the same X variables used in imputation in a weighting approach, then the variances should be the same. This is sometimes referred to as predictive means weights and contrasts with propensity weighting. There was agreement that we should concentrate on using weighting variables that are associated with the Y variables if we are interested in reducing nonresponse

bias. It was argued that since imputation is variable specific, we can make better use of the rich covariates compared to weighting, where one must ultimately create one weight for each respondent as opposed to a weight for each Y variable.

Research Agenda

This session pointed to four major areas of research. First, it is clear that new and innovative research needs to be conducted comparing rigorous probability sampling designs with the continuum of nonprobability methods that have been used or proposed. The availability of external benchmarks can greatly assist this type of research. Even the sampling statisticians at the session agreed that in some situations, the use of probability sampling is not feasible. In that situation, we should not conclude that the survey should not be conducted but rather understand what nontraditional methods are available—for example, what are the tradeoffs between respondent-driven sampling and an opt-in Web panel for sampling a very rare population? We also need to better understand how probability samples can be used to calibrate nonprobability samples.

Second, we need to apply simulation techniques to high-quality/high-effort surveys to understand how reducing effort to save money or speed up the release of survey estimates affects the quality of the estimates. Simulations, if well designed, can determine the impacts of reducing the number of call attempts when rapid release estimates are needed. In the area of weekly rolling samples, it can be used to determine the impact of curtailed field periods to allow for the timely release of rolling weekly estimates.

Third, the use of sequential multimodality surveys without thought being given to building experiments into the designs limits what we are learning from the large number of sequential multimodality surveys being presented at survey conferences. For example, as we move from one mode to another, are we reaching sample groups that differ on our key survey health variables, or are we just seeing mode effects? This makes it very difficult to judge the benefits of using sequential multimodality designs; carefully designed experiments can inform the discussion of whether these types of surveys should be more widely used.

Fourth, imputing for item nonresponse is well accepted by survey statisticians, and multiple imputation is now widely used in surveys. Imputing all variables for unit nonrespondents versus weighting the respondents is an area of active debate and research in the survey statistics community. Most major surveys continue to provide a weight for each respondent. The alternative approach of imputing the nonrespondents is viewed by some statisticians as preferable from the point of view of nonresponse bias reduction when a rich set of sampling frame covariates is available. Part of the argument in favor of imputation is that it is variable specific. Some survey statisticians argue that techniques such as predictive mean weighting (i.e., weighting on variables associated with the key survey health variables) can achieve the same objective with less complexity for the data users. This will be an area of continued debate and research in the survey statistics community for health surveys as well as many surveys about many other subject matters. One aspect of future research should focus on the common situation in the U.S. of not having access to a rich set of covariates in the sampling frame.

One session attendee ended with a comment along the lines that caution should be a watchword, but we need to solve problems. Future research on nontraditional methods should be guided by those this philosophy.

SESSION 4: Building the Health Data Sets of Tomorrow

ORGANIZERS: Michael Davern (NORC), **John Loft** (RTI International), and **Judie Mopsik** (The Lewin Group)
CHAIR: Judie Mopsik

Population Health Research with Health Plan Data Linkage: Building from the HMO Research Network Experience

Michael Von Korff (Group Health Research Institute)

"Change is hard because people overestimate the value of what they have, and underestimate the value of what they may gain by giving that up." (Belasco & Stayer, 1993)

Since the 1970s, the Veteran's Administration, Kaiser Permanente, Group Health Cooperative, and other large integrated health plans have invested billions of dollars in electronic health care data systems to improve health care provided to their patients, more recently implementing comprehensive electronic medical records. As the U.S. transitions gradually toward near universal coverage, larger health plans, and Accountable Care Organizations, high-quality electronic health care data are likely to become available for larger segments of the U.S. population. This change has the potential to transform how population health research is done.

Changes starting to take place include greater use of health plan electronic data in research, more efficient primary data collection through health plans taking advantage of available electronic health care records, and the potential for greater accountability of health plans and researchers for achieving progress towards national health and health care objectives. Experience with population health research in the HMO Research Network can provide insight into how increased availability of high-quality electronic health care data can change the methods of population health research. Examples of the kinds of research that have been carried out using these populations and data resources have been reviewed by Saunders, Davis, and Stergachis (2005) and Selby et al. (2005).

The HMO Research Network (HMORN) is a consortium of 16 research centers located in health plans that serve defined populations with access to high-quality electronic health care data. The 15 HMORN research centers in the U.S. are in health plans with diverse health care delivery arrangements including integrated group practice and network models. The plans serve large, diverse, relatively stable populations. The research centers have access to comprehensive electronic health care data organized in SAS archive files, and they do public-domain health services, clinical, epidemiologic, and behavioral sciences research predominantly funded by NIH, other federal agencies, and foundations.

The combined populations of these health plans include about 11 million people with linked archival health care data. There are now online electronic medical records (EMR) data available for almost 8 million current enrollees. The research centers routinely link these data to state birth and death records. Seniors and children are well represented in the HMORN populations, as are racial and ethnic minorities (see Table 1 on the next page). HMORN health plans serve persons insured by Medicare, Medicaid, and state low-income plans, as well as employer-based health insurance and individual policies. Across the health plans, 57% of persons who enroll remain in the plan three years later, but retention is substantially higher among the subset of these populations enrolled for at least one year.

Table 1. HMO Research Network Population Characteristics across the 15 U.S. Health Plans

Combined population of ~11 million persons with linked archived electronic health care data of high quality
~7.5 million persons with online electronic medical records
State birth & death records routinely linked by research centers
Age **<18 years**: 25% (~ 2.7 million); **≥ 65 years**: 17% (~ 1.3 million)
Racial/Ethnic minorities: 43% (~ 4.7 million)
Includes Medicare & low-income insured populations
Median enrollment retention at **1 year**: 84%; at **3 years**: 57%
Enrollment retention higher for persons enrolled at least one year

Table 2. Emergent Data Resources in HMO Research Network Health Plans

RESOURCE	DESCRIPTION
Biometric data	Height, weight, blood pressure, cholesterol levels, glycemic control, & other biometric measures can be tracked longitudinally on a population-basis for persons with EMR data coverage.
Natural language processing (NLP)	NLP is being used to process clinical text data obtained from health plan electronic medical records.
Genetic data	Saliva samples are being obtained through the mail. Blood samples are collected via health plan laboratories in the primary care clinic of the research participant.
Geographic data	By geocoding address data, HMORN health data are being linked to geographic data (e.g., neighborhood walkability).
Health Risk Appraisal (HRA) data	In concert with employer groups, some HMORN health plans are collecting extensive health behavior & health risk data through online HRAs. These data are becoming available for hundreds of thousands of enrollees.

Over the past 15 years, the HMORN has developed a series of research consortia funded by NIH and other federal agencies, including major initiatives concerning cancer, vaccine safety, cardiovascular disease, and drug safety surveillance, among others. These initiatives include Cancer Research Network (NCI), Vaccine Safety Datalink (CDC), Cardiovascular Research Network (NHLBI), Mental Health Research Network (NIMH), Center for Education and Research on Therapeutics (AHRQ), Mini-Sentinel (FDA), DeCIDE Network (AHRQ), and the Breast Cancer Surveillance Consortium (NCI), among others. NIH currently is working with the HMORN in a collaborative arrangement to facilitate large-scale clinical trials and genetics research.

Most of the HMORN research centers have survey centers with CATI, mail, and Web-based data collection capabilities. The sampling frames available in these populations include not only age, sex, and contact information, but also diagnostic data, information about drug exposures, and other information from the health plan databases. Survey calls are identified as coming from the health plan. Telephone interviews remain the predominant form of survey data collection, but mail, Web-based, and mixed-mode data collection are increasing in use. Many of the research centers have facilities for clinical assessments. Survey response rates have declined in the HMORN populations, but it is routine to achieve response rates in the 60–80% range depending on interview length, the target population, and the research subject. Follow-up rates are generally high—in the 85 to 95% range for a one-year follow-up in a longitudinal study or clinical trial. Demographic and electronic health care data can be compared for survey nonrespondents and respondents, and nonresponse adjustment for variables associated with nonresponse often is employed.

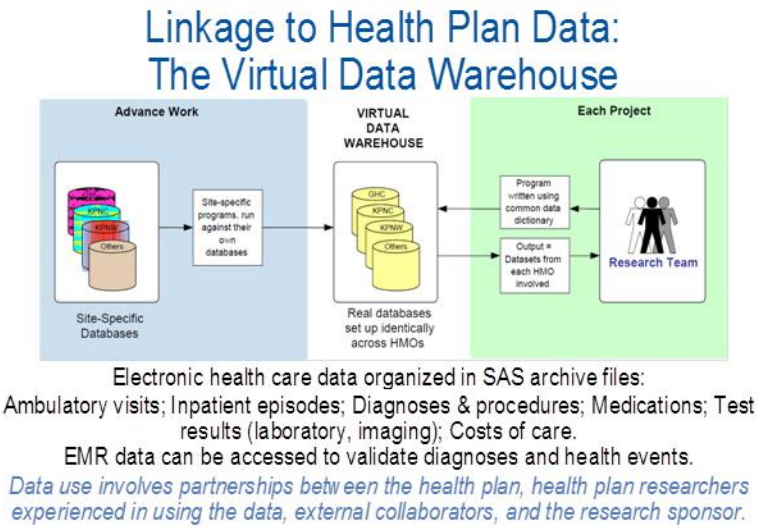
HMORN health plans have unique data resources that are becoming available for millions of enrollees (see Table 2). With the implementation of EMRs, biometric data now are available for entire populations, including height and weight, blood pressure, cholesterol, and (among persons with diabetes) glycemic control. These measures can be tracked longitudinally on a population basis. Natural language processing is

being used to process clinical text extracted from EMRs with some success, and pharmacoepidemiologic research in the HMORN is now using online access to EMR data to validate and refine diagnostic and health event data obtained from administrative data with considerable success. Medical record abstracting using the EMR is substantially more efficient than abstracting paper charts, and highly efficient electronically guided chart reviews are being used. There is growing experience with collecting saliva samples via mail and blood samples in health plan laboratories located in the primary care clinics of research participants. There is also growing use of geographic data obtained by geocoding address data, permitting analyses that link health plan data to environmental characteristics such as neighborhood walkability.

Some of the health plans are collecting extensive Health Risk Appraisal (HRA) data through online HRAs implemented in concert with employer groups. HRA data are becoming available for hundreds of thousands of enrollees, and coverage should increase in coming years. The health plans are developing unique and valuable data resources that can be used for research and for tracking progress towards national health and health care objectives.

While health plan data are archived in SAS files and routinely are used in research, access to these data is generally obtained through researchers working within the health plan. There is not a national data archive. Rather, multiplan data analyses are developed through what is called the Virtual Data Warehouse or VDW (see Figure 1). The VDW involves running site-specific programs developed from common algorithms against databases that have been set up to be comparable across health plans. The research team analyzing VDW data obtains access to de-identified variables created by the common algorithms but not the original health plan data. Data use involves partnerships between the health plans, health plan researchers, external collaborators, and often the research sponsor. Progress has been made in making IRB processes for approving multisite use of HMORN data more efficient. Major multisite analyses of VDW are now routine.

Figure 1. The HMO Research Network Virtual Data Warehouse (VDW)



The kinds of data and data collection capabilities now accessible through health plans would have been hard to imagine even 20 years ago. The way research with these data is carried out has changed incrementally, but the end result has been fundamental change in the methods of population health research. Over the next decade, the percent of the U.S. population covered by health plans with high-quality electronic health care data will increase dramatically. The transition to population health research using these data is underway, and these trends will accelerate as population coverage increases.

Figure 2. Building a Learning Health Care System

Enlisting health plans as research partners could develop "learning health care systems."

As these changes play out, there is the potential for large health plans and accountable care organizations to emerge as key partners in the conduct of population health research. These changes are potentially beneficial for the health of the American population, as health plans are ultimately accountable for dissemination of evidence-based best practices for prevention, health care value and safety, and chronic illness care.

If we are to improve health outcomes and control health care costs, we need health plans that function as "learning health care systems" (see Figure 2). In such a system, research influences practice, and practice influences research. Enlisting health plans as research partners could help us develop learning health care systems capable of addressing the challenges associated with reorganization of health care services that lie ahead. At Group Health Cooperative, for example, the relationship between the health plan and the research institute has developed in ways that increase the impact and relevance of research. If this happened on a national scale, we would be in a much better position to control health care costs and improve population health outcomes.

How could national research policies become more effective in achieving national policy objectives? A first step would be to recruit health plans as partners in carrying out major research initiatives relevant to national objectives. Such initiatives could form partnerships between academia, government, and health plans to conduct policy-relevant research and to change how health care services are delivered in the process. Such partnerships would view health plan data as a national asset for achieving policy objectives.

Through efficiencies of scale, technological innovation, and health plan engagement, it could be possible to dramatically reduce the costs of primary data acquisition with linkage to health plan electronic health care data resources. Major research initiatives then could be used as a means of increasing the accountability of health plans—and of researchers—for achieving national health and health care objectives. Such initiatives could draw on methods that are being used now (see Table 3 on the following page).

Using the health plan as a sampling frame and baseline data acquisition through the health plan Web-based data portals that enrollees are already using, it would be possible to enroll literally millions of

Americans in a national cohort dedicated to achieving aims such as improving health outcomes and reducing health care costs, discovering the causes of major diseases and disabilities, and ensuring that treatments being administered are safe and effective.

Baseline data might be collected using a standardized Web-based Health Risk Appraisal (HRA). The HRA could be promoted to health plans as a strategy to engage their enrollees in a national initiative with far-reaching opportunities to improve health and lower health care costs. Participation might be incentivized with reduced out-of-pocket health insurance premiums.

Once a national cohort was enrolled with comprehensive baseline data, it would be possible to track biometric measures, disease occurrence, treatments, health care use and costs, and selected health outcomes using health plan electronic health care data. The electronic health care data could be supplemented with targeted primary data collection in subsets of the national cohort. Appropriate data sharing mechanisms could be developed to permit large-scale use of national cohort data by researchers in academia and government and policy research organizations, as well as researchers working in health plans.

Through partnerships with health plans, it would be possible to implement major trials of preventative interventions and innovations in health care delivery within segments of the national cohort. Self-reported health measures could be obtained by interview or Web-based data collection in subsamples. Genetic data also could be collected in subsamples through standing orders administered by health plan laboratories activated when patients make a health care visit.

This sort of research endeavor could serve as a basis for clarifying the accountabilities of health plans and of researchers for achieving national policy objectives through discovery of effective innovations and dissemination of evidence-based best practices. Such an initiative might close the gap that currently exists between policy research and research funded by NIH for scientific discovery. It also could drive down the aggregate costs of data acquisition that currently are outpacing national funding resources. Fundamental change in the way we organize population health research is not only possible—it is necessary if we hope to make our research more effective in achieving national policy objectives.

Table 3. Building the Health Data Set of Tomorrow Using Methods in Use Today

Efficiently enroll millions of Americans in a National Cohort dedicated to • Improving health outcomes & reducing health care costs • Discovering causes of major diseases & disabilities • Ensuring that treatments are effective & safe
Collect baseline data through a standardized online Health Risk Appraisal promoting it as a strategy to engage health plan members in a national initiative with far-reaching opportunities to improve health outcomes & lower health care costs. Incentivize participation with reduced out-of-pocket health insurance premiums.
Track biometric measures, disease occurrence & treatments, health care use & costs, & health outcomes using health plan electronic health care data supplemented by targeted primary data collection.
Implement major trials of preventative interventions & innovations in health care delivery within segments of the national cohort.
Measure self-reported health outcomes in targeted subsamples by telephone survey and/or online data collection.
Collect genetic data in targeted subsamples through standing orders administered by health plan laboratories activated when patients make a health care visit.
Define accountabilities of the health plans & researchers for achieving national health policy goals through discovery of effective interventions & dissemination of evidence-based best practices.

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The Use of Cognitive Interviewing to Evaluate Data Quality in Administrative Records

Stephanie Willson (National Center for Health Statistics)

INTRODUCTION

Evaluating administrative data is becoming more salient as the federal statistical system has been expanding—and likely will continue to expand—its use of administrative records. This paper argues that cognitive interviewing, a methodology typically associated with survey question evaluation, is an appropriate and helpful tool for evaluating administrative data quality. This paper draws on a study conducted by the Questionnaire Design Research Laboratory (QDRL) at the National Center for Health Statistics aimed at understanding how select medical and health items on the Facility Worksheet for the 2003 Revision of the U.S. Standard Certificate of Live Birth are collected. The cognitive interviewing method helped us understand the patterns of different processes by which the abstraction of birth certificate data take place, where the process deviates from the federally recommended standards, and the possible causes of error in birth certificate data. As a result, we feel the method can be successfully applied to the evaluation of data quality in various types of administrative data.

ADMINISTRATIVE DATA & THE JUSTIFICATION FOR USING COGNITIVE INTERVIEWING

Defining Administrative Data

Administrative data can take many forms. For the purposes of this paper, I am including hospital records (e.g., medical records and billing records) and state vital records (e.g., birth and death certificates) as examples of administrative data. It's important to recognize that administrative records are used in different ways, which can impact what the data look like. Sometimes administrative records are used in validation studies as a "gold standard" against which survey estimates are compared. For example, survey estimates of health insurance coverage (both public and private) have been compared against Medicare, Medicaid, and Blue Cross/Blue Shield records (Blumberg & Cynamon, 1999; Davern et al., 2008). Other times, administrative records have been linked to survey data to augment analytic power. The National Health Interview Survey has linked death certificates in order to obtain a more complete picture of cause of death (see Denney, 2010; Klatsky, 2010). In these examples, the administrative records are *themselves* the data.

In other instances, administrative records are not used as data in-and-of themselves but are instead modified and adapted to serve research purposes. In this case, they are a *source* of data but are not used directly *as* data. As a result, information must be either extracted or abstracted from the record and transformed into a more "useable" form. Extraction is generally easier because it involves a literal transcription of a piece of information from one place to another. Abstraction is more complicated because information from the administrative record must be altered in some way in order to suit the purposes of the research agenda. The focus of this paper is on the latter—administrative records as a source of data.

Justifying the Use of Cognitive Interviewing

Traditionally, cognitive interviewing primarily has been used to evaluate survey data. For surveys, a respondent is the source of data. Health survey questions ask respondents about their life, their experiences, or even their opinions on certain topics. With administrative data, on the other hand, the record is seen as

the source of data. Despite these perceived differences, data quality is a consideration in both. With surveys, attention must be paid to the amount and nature of measurement error associated with a particular question. With administrative records, it's easy to assume that the information is self evident. Because it doesn't involve the interaction of an interviewer posing a question to a respondent—which can be fraught with communication difficulties—the data are seen as more reliable and the process as more straightforward. Instead, accuracy and completeness of the record are recognized as the potential problems.

With surveys, cognitive interviews are used to assess the data that come from asking questions. With administrative records, when data quality is assessed, it is most often done by repeating or observing the abstraction process to assess data reliability or, for computerized records, it can include range and logic checks for things like dates. However, we feel that more can and should be done to evaluate the quality of data obtained from administrative records. My assertion is that although cognitive interviewing has been used predominantly for evaluating survey data quality, it also can be used to evaluate and explicate administrative data.

Traditional Model of Cognitive Interviewing: Exploring the Question-Response Process

Cognitive interviewing, as a qualitative methodology, is a tool for exploring how respondents go about answering a survey question. The model most commonly used to explicate this phenomenon is Tourangeau's four-step process of comprehension, retrieval, judgment, and response (Tourangeau, Rips, & Rasinski, 2000). When answering a survey question, respondents must first understand what it's asking. Second, they must recall relevant information from memory. Next they make judgments about the applicability of the information they have recalled. Finally, they map the answer they have arrived at in their mind onto the response categories provided for the question. Cognitive interviewing taps into this process in order to determine where things can go wrong (in each of those steps) and to evaluate and describe the construct validity of each survey question (Willis, 2005). The ultimate goal is to design a survey question that accurately captures the intended construct.

Adapting the Traditional Model: Adding Structure & Process

The question-response model can, and has been, extended for use beyond traditional surveys. For example, Edwards and Cantor (1991) and more recently Willimack and Nichols (2001; 2010) modified the model for establishment surveys. The original steps still apply and have utility, but Willimack and Nichols add steps to reflect the realities of the collection of data from businesses.

In working with administrative data obtained from hospitals, I find utility—both theoretically and empirically—in the way Willimack and Nichols adapted Tourangeau's model. However, this paper emphasizes the process as more of a multidimensional (rather than linear) one because the abstraction of administrative data occurs in different ways and at different levels, sometimes simultaneously. Willimack and Nichols (2010) emphasize the benefits of the modified model to be exclusively in the identification of measurement error "so that the survey design may be altered to reduce or eliminate such error" (p. 19). While the identification of measurement error is an important endeavor, I argue that cognitive interviewing can be extended to reveal patterns of process and structure that give a more complete meaning behind what is being captured by items in different organizational contexts for specific surveys.

Administrative personnel, nurses, and physicians create medical records. In this study, I focused on the abstraction of data from hospital administrative records and identified four phases in the process that potentially impact data quality. First, the person abstracting the data first has to understand and interpret the

administrative record. Second, in the process of abstracting data from records, there is often some kind of worksheet. This worksheet also has to be understood and interpreted. On a third level, the abstraction process itself must be understood and interpreted by the data collector. In essence, this is the understanding of how people interpret the connection or relationship between the administrative record and worksheet. Finally, the way the job is structured can play a role in how data are abstracted. This is perhaps the biggest modification of the original Tourangeau model because it adds sociological insight to a largely psychological model. For example, if the process of abstraction is structured differently in different locations, the nature and quality of the data will be impacted. If one location uses doctors to abstract data and another uses administrative clerks, the process and all the other steps will occur very differently. Hence, data are less likely to be comparable across sites, and the difference is likely to be patterned and systematic.

The way this occurs is not necessarily a linear process. Instead, each of these processes (understanding the worksheet, understanding the administrative record, understanding the process, and the structure of the task) interact together and often occur simultaneously to produce administrative data. Cognitive interviewing can shed light on how each of these processes function, as well as how they work together to tell us something about the nature of the data they produce. The next section provides a specific example of these ideas. It discusses how these processes were identified and studied in the QDRL birth certificate study.

THE BIRTH CERTIFICATE STUDY

The birth certificate study covered four states in different parts of the country. Each state had experience with the 2003 revision; however, states (and even hospitals within each state) modified the revised certificate of live births to suit their own needs. A total of 54 interviews were conducted with Birth Information Specialists in hospitals.

The goal was to discover how hospitals structure the task of abstracting data on live births, how hospitals go about completing the task, and how they interpret various items on the worksheet. Cognitive interviews were conducted with the worksheets each state uses to collect birth certificate information prior to entering the information into the Electronic Birth Certificate (EBC) system. The birth certificate worksheets consist of essentially two parts: the first contains information that becomes part of the official birth certificate given to parents, and the second part contains medical and health information related to the mother and the birth. The focus of data abstraction was on part two (the medical and health information portion of the birth certificate worksheets). For example, probing centered on specified pregnancy history and prenatal care items, as well as all other medical and health information items. Interviews took place with hospital employees responsible for completing the state form and for transmitting data to the EBC database.

Aside from exploring the interpretive aspects of individual items on the birth certificate worksheet, another goal of the project was to discover how hospitals structure the task of collecting data on live births, as well as how hospital personnel go about completing this task given day-to-day realities in a hospital. The question to be answered was if and how the structure of the job and the process of completing the forms impact the data being collected. We used cognitive interviewing to explore process and structure in addition to interpretation. During the interview, the researcher collected detailed information on how the form was being completed from start to finish and respondents' understandings of their role in the process. We also explored how responsibility for completing the forms was organized by each hospital and the extent to which that protocol was followed. Interviews usually began with a discussion of how the worksheet is envisioned to be completed in that hospital, followed by an explanation of how the form actually *is* filled

out. Respondents were prompted to discuss any problems they encounter in completing the worksheet and how they resolve these problems.

Results

A primary finding is that there is great variability among hospitals in the abstraction process. This variation creates differences in the data produced on the birth certificate worksheet resulting in a lack of data comparability among states. For example, if higher Cesarean rates are observed in one state compared to another, that difference may be an artifact of how the data are produced and not attributable to a true difference in Cesareans. Four sources of variability were identified.

One source was in Birth Information Specialists' interpretations of items in the medical records and on the birth certificate worksheet. Understandings of various terms and medical phrases were not consistent among the specialists. The item on whether the mother was breastfeeding upon discharge from the hospital is a good example. Respondents were sometimes confused over the definition of breastfeeding. Some wondered whether one try counts. If not one try, then how many? (At what point does the answer go from no to yes?) Others did not know if pumping counts. They wondered if the point was in knowing only that the infant is ingesting breast milk or in knowing that the bonding process is occurring as well. Relatedly, some respondents were not certain how to record information when the mother was choosing to both bottle and breastfeed. They weren't sure if the item was designed to capture 100% breastfeeding or if "part-time" breastfeeding counted.

Second, there was variability among states in worksheet design. Some states used separate sheets for different sections while others put all information on one sheet (front and back). Moreover, absent any instruction (as was usually the case), it was unclear who should complete each section of the form—the mother or a clinician. As a result, different people were completing different sections, both among hospitals and among states. This variability is noteworthy to the extent that some people are better suited than others to complete certain items. For example, clinicians are better suited than mothers to fill out the medical and health information section. Mothers cannot necessarily be expected to know medical terms. For example, one item on the worksheet asks whether there was "moderate/heavy meconium staining of the amniotic fluid." This item can be difficult for many laypeople to answer. Federal recommendations regarding who should complete certain items do exist, but deviation from and variation in the structure of the worksheet used by individual states contributed to those recommendations being overlooked.

Third, there was variability in who is responsible for getting medical and health information from medical records. In some states, the Birth Information Specialists are responsible for this information; in other states, clinicians are responsible; and in a few cases, the mother is responsible. Despite federal recommendations that encourage a unified approach, states and even local hospitals structured this task differently. This is an important finding because each group (mothers, birth clerks, and clinicians) has different levels of knowledge and understanding of items on the worksheet and of the medical records (the chief source of information for items on the worksheets).

Finally, there was variability in how certain items were collected (e.g., pregnancy history items vs. other medical and health information) by Birth Information Specialists. Some respondents would use the medical records for the medical and health information, but ask the mother for pregnancy history items. Others would ask the nurse for all information or ask the mother for all information. The medical record was consulted only when nurses or mothers could not provide the requested information.

Additionally, when information is missing from the medical records (not an uncommon phenomenon) or is not stated in a straightforward manner, many Birth Information Specialists developed another strategy to

come up with information to record on the birth certificate worksheets. This involves making a logical assumption as to what the answer would be based on other available and relevant information. One respondent referred to this as "putting two-and-two together," and another called it "estimating." I refer to this process as "logical estimation." This tends to occur when a key piece of information they need is not directly available in the medical record. However, other information can provide insight into what the missing value would be. Unfortunately, this is not always a straightforward process and can lead to inconsistent conclusions. Trial of labor is a good example. For mothers who had Cesarean deliveries, the item on the worksheet asks, "Was a trial of labor attempted? Yes/no." Nowhere in the medical record does it explicitly state, "trial of labor was attempted." So birth clerks usually have to read through the labor and delivery log to determine the answer to this question. Some said that if they see that the mother had a previous Cesarean delivery, they assume that no trial of labor was attempted and mark 'no' on the worksheet. This, of course, may not be the case. Some mothers do delivery vaginally after having a Cesarean. Another example of frequently missing information is date of last normal menses. To arrive at a logical estimate for this, many respondents use the mother's expected date of delivery to calculate the date of her last period. However, as women's menstrual cycles are sometimes quite unpredictable, this has the potential to introduce variability and error into the data. This lack of standardization at many points and on different levels in the process resulted in data that are not comparable and draws into question the validity of certain items.

CONCLUSION

The cognitive interviewing method was very good at helping us understand the patterns of different processes by which the abstraction of birth certificate data takes place, where the process deviates from the federally recommended standards, and the possible causes of any error in birth certificate information. It was shown that the method is not limited to its traditional use of the four-stage model of question-response (comprehension, retrieval, judgment, response). It also can incorporate sociological insight by examining the structural features of the creation of data, and how these features impact data quality. The findings from this study were used to create new federal recommendations for the abstraction of birth certificate data, with an eye toward improving data quality.

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Issues in Designing and Fielding High-Quality Surveys of Physicians and Medical Group Practices

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INTRODUCTION

Surveys of physicians and medical groups are widely regarded and frequently employed as a cost-effective and meaningful way to obtain information about many aspects of clinical care and the health care settings in which care is delivered. This type of health survey is a particularly important source of information on physicians' knowledge, attitudes, opinions, and practices related to new or controversial technologies, clinical practice guidelines, decision-making regarding specific interventions, and motivation/barriers to changing their clinical practices. Yet physicians are a challenging population to survey, and surveys of physicians generally attain response rates that are ten or more percentage points lower than those of the general population; further, recent evidence suggests that response rates to physician surveys may be declining. Given the central role of physicians in implementing new standards of care, guidelines, new technologies, and health care reform, obtaining information about their practices and perspectives via surveys will remain a critical need for health services and policy researchers.

In November 2010, the National Cancer Institute convened a one-and-a-half day Provider Survey Methods Workshop to review and discuss current methodologies in designing and fielding large-scale surveys of physicians and medical group practices, as a means of informing future efforts in developing valid, high-quality provider surveys. Goals of the workshop were to

- Describe methods used in fielding and reporting on large-scale surveys of physicians and medical group practices published in the U.S. during the period 2000–2010.
- Identify and discuss the most effective methodologies for fielding valid, high-quality surveys among physicians and medical group practices.
- Highlight opportunities for methods research in surveys of physicians and medical group practices.
- Consider the need to develop reporting standards to enhance understanding of the methods used in surveys of physicians and medical group practices and assessments of survey quality.

The workshop was organized around four topics: (1) sample frames for surveying physicians and medical practices, (2) point of contact and survey administration modes, (3) respondent incentives, and (4) questionnaire design, topic, and burden. Prior to the workshop, a literature review to identify publications involving completed surveys and methodological studies was conducted. During the workshop, presentations covering the four topic areas were provided by 15 subject matter experts, with extensive discussion by workshop participants following each session. A three-member expert panel offered reflections and prompted further discussion on future prospects for conducting high-quality surveys of physicians and medical practices. This paper summarizes key findings and recommendations from both the literature review and the workshop.

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LITERATURE REVIEW

A background literature review was conducted in 2010 to identify methodological variables that may be associated with the quality of provider survey data. The review was restricted to large-scale health care provider surveys fielded between 1998 and 2009 (and published between 2000–2010) that had at least 500 or more respondents. A search of the peer-reviewed and the "grey" literature (e.g., unpublished reports available on the Internet) was conducted. The source of the peer-reviewed literature was PubMed, whereas Google and federal agency Web sites were the sources of the grey literature search. For all information sources, the following search terms were used: *physician*, *health care provider*, *nurse*, *physician assistant*, *survey*, *questionnaire*, *national*, *methods*, *incentive*, and *response rate*. Over 6,700 citations initially were identified. Eighty-eight survey projects met the eligibility criteria, and detailed information about them was abstracted, including survey topic, dates fielded, sponsor, type of provider surveyed, sampling frame, initial sample size, survey mode, survey length, incentive, follow-up strategy, response rate, and method for calculating the response rate.

In over 90% of the survey projects, physicians (as opposed to, for example, medical practices) were the provider type surveyed. Eighty percent of survey projects used the American Medical Association (AMA) Physician Masterfile, specialty society mailing lists, or state licensing board databases for the sampling frame. Seventy-five percent of survey projects employed mail as the survey administration mode, 11% used the Web, 8% used more than one mode, and only 2% used telephone. Forty-three percent of survey projects reported the length of the survey in terms of the number of items, 25% reported the number of pages, and 31% did not include information about survey length or burden. Monetary incentives were more common than nonmonetary, and contingent incentives were more common than noncontingent. However, for nearly half of the survey projects, either no incentive was used or the type of incentive was not specified. The most common method of nonrespondent follow-up was an additional mailing, followed by the use of an additional mailing plus telephone reminder calls. In nearly 25% of the survey projects, however, either no follow-up method was used or this was not mentioned in the survey description. Nearly half of the surveys in the literature review achieved a response rate of 60% or higher, but reporting of response rates was inconsistent, and it was not always clear from the survey documentation whether a response rate (versus a cooperation rate) had been computed. Further, whether a response rate fit any particular standard definition as defined by the American Association for Public Opinion Research (AAPOR) often was unspecified. In particular, publications tended to lack information concerning whether providers who could not be located were included or excluded from the denominators of response rates, and eligibility was not always clearly described.

KEY DISCUSSION POINTS FROM THE WORKSHOP

Sample Frame

In surveys of physicians, particularly those that are national in scope, the AMA Physician Masterfile has been the most commonly used sample frame, as this source is regarded by many researchers as providing a high level of coverage. On the other hand, the Masterfile also has the drawback of containing a considerable amount of out-of-date information, which poses challenges to survey researchers who require accurate eligibility and contact information for fielding a valid and efficient physician survey. Workshop attendees agreed that linkages of survey samples drawn from the Masterfile to other physician databases, such as the American Medical Information (AMI) or National Provider Identifier (NPI) files, might provide a cost-effective means for obtaining up-to-date eligibility and contact information but that such methods are yet to be developed.

Another conclusion was that identification of appropriate sample frames for surveys of medical groups, as opposed to individual clinicians, has proved to be particularly challenging. No single, comprehensive national database for the study of medical groups in the U.S. exists. As it is increasingly important to obtain information from groups of providers, there is need for a single sample frame that enumerates both physicians and the organizations in which these physicians provide clinical care. Given the decentralized nature of health care delivery in the U.S., it is likely that one or more federal government agencies would need to take a lead role in creating and maintaining a comprehensive national sample frame of physicians nested within medical groups and other health care organizations.

Survey Administration Mode

Consistent with the findings from the literature review, workshop attendees noted that over the past decade, most large-scale provider surveys have used mail as the administration mode. Telephone surveys, especially of physicians, have become exceedingly rare. Further, compared with mail surveys, those conducted by Web or e-mail attain lower response rates. A small proportion of provider surveys have been conducted using more than one administration mode. It is not clear, however, whether offering a choice of mode results in higher response rates, and it is possible that providing choice sometimes lowers response rate. Given growing use of the Internet, it will be important in designing future provider surveys to optimize a mixed-mode approach (i.e., mail and Web). It was suggested that mode will undergo dramatic change over the near future and that 15 or so years from now, all surveys (including those of providers) essentially will be paperless.

Incentives

Presentations and discussion at the workshop suggested that in surveys of physicians, use of monetary incentives appears to contribute to higher response rates than do nonmonetary incentives. Likewise, noncontingent incentives (those normally delivered prior to survey completion) appear to contribute to higher response rates than do contingent incentives (those delivered after completion). A major theme emerging from the workshop was that the optimal or ideal monetary incentive for surveys of physicians has not been well established. It is clear, though, that incentives rarely take into account other staff in the physician's office who serve as gatekeepers and who themselves may need to be incentivized. The attendees agreed that there is a critical need for further methodological study to determine how best to optimize incentives in provider surveys and that this work should include gatekeepers in medical practices.

Follow-up Strategy

Although it is widely acknowledged that follow-up of nonrespondents is an important component of the survey process, workshop participants felt that it is not known which follow-up strategies are the most effective in surveys of physicians and medical groups. As made clear by the literature review, well-documented studies have reported a variety of follow-up strategies, including increasing the intensity of use of the initial contact mode (e.g., repeated telephone calls), diversifying the contact mode (e.g., use of both telephone and mail), and offering additional incentives to nonrespondents. However, follow-up strategies are not consistently documented in survey publications and do not appear to have been empirically tested in a systematic way. Therefore, a major conclusion from the workshop was that a promising area for future research would entail assessing the effectiveness and efficiency of various follow-up strategies for improving response in surveys of physicians and medical groups.

Questionnaire Design, Topic, & Burden

The quality of survey data can be optimized through carefully designed questionnaires that address a topic salient to the respondent and impose low response burden. Pretesting strategies such as cognitive testing, focus groups, and pilot studies are important tools for informing questionnaire design and assessing topic salience and response burden. Yet, our literature review made clear that in most literature describing surveys of physicians and medical groups, there is a general lack of detail about the questionnaire design process, with the exception of surveys sponsored by federal agencies. Moreover, there has been no systematic attempt to conduct research to determine how questionnaire design, topic, and burden influence the data quality within health care provider surveys. Nevertheless, workshop participants suggested it is likely that time-pressured physicians respond best to survey questions that are presented in a clear, concise, logical manner, and to response formats that minimize burden. Further, researchers should give consideration to identifying practice staff other than the physician who might be able to respond to certain questions as a means of minimizing burden on busy clinicians.

Response Rates

Reiterating the literature review, workshop presentations and discussion concluded that there is poor and variable documentation of response rates in literature describing surveys of physicians and medical groups, even though researchers themselves, journal editors, and journal reviewers tend to regard response rate as a key indicator of survey quality. In particular, participants noted that even when response rates are reported, further scrutiny may reveal that the reported "response rate" is actually a (more liberal) "cooperation rate." Few papers have reported both measures, and the AAPOR standards for calculating survey response rates are seldom cited. The poor and variable documentation of response rates makes it difficult to compare response rates across surveys or to draw conclusions about the quality of the data collected in the survey.

CONCLUSIONS

In this paper, we summarize both the results of a literature review on methods used in fielding and reporting on large-scale surveys of physicians and medical group practices conducted in the U.S. during the last decade and discussion points from a workshop convened by the National Cancer Institute in November 2010 to inform future efforts in developing and fielding valid, high-quality surveys of health care providers. Key conclusions from the review and workshop were that there is great need for

1. Improved sample frame databases, especially to allow study of providers nested within health care organizations.
2. Empirical study of how to optimize mixed-mode surveys (i.e., mail and Web) of health care providers, given that mail remains a viable mode and the Web is anticipated to become increasingly prominent over the next decade.
3. Empirical study of incentives and their utility among gatekeepers, especially within surveys of medical group practices.
4. Empirical study of factors that motivate or impede the participation of physicians and other health care providers in survey research.
5. Most importantly, better documentation in journal articles and other literature of the methods used in health care provider surveys, particularly of pretesting procedures, follow-up strategies, and response rate calculations.

Collection of Biomarkers and Linkage of Administrative Data in the Survey of Health, Ageing and Retirement in Europe

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INTRODUCTION

Population aging in Europe is one the major challenges of the 21st century. Up to now, we have insufficient information to understand how population aging affects the living conditions of older people and their families, and we do not know much about how state policies may influence these living conditions. In order to tackle this challenge, the European Commission placed a call to researchers in Europe to build up infrastructures to learn more about our aging societies. Following this call, the Survey of Health, Ageing and Retirement in Europe (SHARE) explores Europe's "natural laboratories" across many scientific disciplines and over time, as SHARE is designed as a panel survey. The infrastructure created by SHARE provides a rich data source for evidence-based policies.

SHARE became an innovative and unique infrastructure as it combines three major strengths: *First*, SHARE is *ex ante* harmonized across countries. This allows researchers to compare the effects of different health and welfare systems in Europe on individuals as well as on families. *Second*, SHARE is multidisciplinary: SHARE researchers come from many different disciplines such as demography, economics, sociology, epidemiology, psychology, gerontology, medicine, and public health. SHARE aims to fill the research gap of the interaction between health and socioeconomic factors. *Third*, SHARE is a longitudinal study. Since aging is a process and not a state, the same individuals are interviewed repeatedly every two years, enabling researchers to learn more about individual aging processes and how these processes are influenced by ongoing political and social changes.

The SHARE success story started in 2004 when the first interviews were conducted in Sweden, Denmark, The Netherlands, Germany, Belgium, France, Switzerland, Austria, Spain, Italy, and Greece. Two years later, SHARE started its longitudinal dimension by re-interviewing respondents from the first wave. Additionally, Ireland, Czech Republic, Poland, and Israel joined the SHARE survey. In wave 3, SHARE collected life histories from the wave 1 and wave 2 respondents—the so-called SHARELIFE project. At that point, SHARE mainly was funded by the EU framework programmes 5 to 7 and the U.S. National Institute on Aging (NIA; for a full list of funding institutions, see www.share-project.org) and collected more than 100,000 individual interviews from Europeans age 50 and older. Wave 3 also marked the beginning of a pilot project within SHARE: the linkage of administrative data from the German Pension Fund (Deutsche Renterversicherung [DRV]) to SHARE survey data. This ongoing pilot project is funded by the German Volkswagen Foundation.

Currently, the panel data of wave 4 is being collected and includes some further additions and novelties. Five new countries joined the SHARE family: Portugal, Luxemburg, Slovenia, Hungary, and Estonia. The sample in many SHARE countries was expanded, resulting in a much larger sample sizes in these countries. Furthermore, a new social network module enriches the SHARE questionnaire. Last but not least, SHARE started collecting biomarkers in a German pilot project, also funded by the Volkswagen Foundation.

SHARE is a member of a family of aging surveys around the world, such as the U.S. Health and Retirement Study (HRS) or the English Longitudinal Study on Ageing (ELSA), and stimulated follow-up projects all around the world, especially in Asia (e.g., the Longitudinal Ageing Study in India [LASI], the

Korean Longitudinal Study of Aging [KLoSA], the Japanese Study on Aging and Retirement [J-STAR], the Chinese Health and Retirement Longitudinal Study [CHARLS]). The common aim of these sister studies is to provide researchers with comparable data that enable empirical research from a cross-cultural perspective.

CLOSING THE GAP—A NEW PERSPECTIVE OF EMPIRICAL RESEARCH ON AGING IN GERMANY

While aging research has made several remarkable achievements in many areas (an overview can be found in Wahl & Mollenkopf, 2007), there is still need for a better integration of previous results and future research projects across disciplines that takes into account the *complex interdependences between biological-medical and socioeconomic factors in the aging process*, both at individual and societal levels.

This research gap is the starting point for a German pilot project within SHARE, which is funded by the Volkswagen Foundation and will be expanded to more participating countries. This project exploits the existing SHARE data infrastructure in order to create a comprehensive database, consisting of the following:

1. Information on the current living conditions from waves 1, 2, and 4 of SHARE
2. Retrospective life histories from wave 3 (SHARELIFE)
3. Administrative process data from the German Pension Fund
4. Objectively measured biomarkers

This generates a basis for the integration of interdisciplinary research on aging, since the separation between medical-biological and socio-gerontological research on aging is an impediment to the development of measures that help improve the quality of life of older individuals.

Our pilot project focuses on *intervention points* in the life cycle. We understand both medical and socioeconomic interventions, which can—sometimes with a substantial time lag—affect the morbidity, mortality, and quality of life of persons at age 50+. A "social management" of aging processes must address such intervention points, and in most cases, the effects of such interventions depend on interrelated health and socioeconomic factors.

While many correlations are known, it is not well understood which concrete causal mechanisms drive the interactions between interventions and environment; neither is well understood which interventions are the most effective in improving the quality of life. For example, it is still not clear

- What causal and especially biological mechanisms are the basis of the observed *strong relationship between socioeconomic status and health*;
- How *measures of social policy* (e.g., reducing eligibility periods for unemployment benefits for older employees by the German Hartz IV laws) affect the health of older persons; and
- How the interaction between biological processes of aging and individual attitudes and expectations affects *health behaviors* (e.g., with regard to prevention).

These three examples demonstrate that a better understanding of causal mechanisms—and this implies better recommendations with respect to interventions—only can be reached by *combining medical-biological insights with knowledge about the socioeconomic environment of individuals*.

Examples for extremely fruitful combinations of biomedical and socioeconomic research and proof of its successes come so far most often from the United States. Two examples include the Aging Center of the RAND Corporation in Santa Monica, California, and the very successful Schools of Public Health—for

example, at Harvard or at Johns Hopkins University. They provide role models for our pilot project and show that we pursue a very realistic goal.

This pilot project includes several project partners: the German Pension Fund (DRV), the Network Aging Research (NAR, an interdisciplinary research network on aging locted in Heidelberg and Mannheim), and the German Cancer Research Center in Heidelberg ("Deutsches Krebsforschungszentrum," [DKFZ]). The project is divided into two parts: part one is the collection and compilation of an empirical database, which will be available free of cost to the research community. The second part of the project enfolds the analysis of the data regarding certain research questions. Special attention will focus on two areas of research: aging research (as described above) and methodological research.

LINKAGE OF ADMINISTRATIVE DATA WITH SHARE

Survey data can cover a wide range of topics. However, the information provided by respondents is often incomplete or inaccurate. On the other hand, administrative data is—in an ideal world—complete and accurate. The disadvantage of administrative data is that the information is limited to a certain topic only. Linking survey data with administrative data is a way to combine the best of both worlds, which offers several benefits.

1. Respondent self-reports are often subject to recall bias. Comparing administrative data with survey data can help to estimate the extent of the recall bias or to validate the survey data.
2. The linkage leads to an improved measurement of the explanatory and dependent variables. This reduces the bias and increases the precision of model estimates.
3. Using administrative data can reduce respondent burden. For instance, aging surveys can benefit from adding Social Security records to explain retirement behavior or measurement of economic resources during retirement. Doctors' or health insurance records can be used to improve the measurement of health.

Experience from other countries shows the great value of the combination of survey data with administrative health and social records (e.g., Lillard & Farmer, 1997).

Since 2001, the access to administrative data for research reasons is much easier in Germany due to the new Research Data Centers ("Forschungsdatenzentren" [FDZ] ; Gramlich, Bachteler, Schimpl-Neimanns, & Schnell, 2010). The goal of the cooperation project between SHARE and the German Pension Fund (DRV) is to link survey data with administrative records held by the DRV. The method of linking different data sources depends on legal as well as technical possibilities of each single data set. First, one has to define the type of data linkage:

- Link data sources of the same person
- Link data sources of people who are similar (in a statistical sense)

The linkage project within SHARE is based on a direct linkage, which means that different data sources from exactly the same person will be linked. The starting point of this project is people who participated in the SHARE survey. By means of the respondent's Social Security number, which is collected with an extra form during the interview, it is possible to identify the records of the respondents in the DRV database, which is primarily used to calculate the entitlements and value of public pension benefits.

For research purposes, the DRV allocates a scientific use file that includes a random sample of all records (for privacy reasons with less detailed information on the individual level). For SHARE, the DRV

creates a data set in exactly the same format as the scientific use file that consists of the SHARE respondents who gave their consent to the linkage.

The data consist of two parts: The first part includes sociodemographic characteristics (age, gender, number and age of children, education) and information about important aspects for the calculation of the public pension (as accumulated *earning points* ["Entgeltpunkte"]). The second part is implemented as a panel database beginning in the year the person is age 14. Beginning on that date, very detailed information about the working history (e.g., employment status and the corresponding earning points) is available on a monthly basis, including unemployment periods and all activities or states that generate entitlements for public pension. The information will be updated with each wave of SHARE so that the panel is continuing.

Privacy laws in Germany require respondents' written consent when directly linking survey data with administrative data on the individual level. The SHARE consent process consists of two steps:

1. The first step is verbal consent at the end of the SHARE interview. The respondents are asked for their consent to link their survey data with the administrative data held by the DRV.
2. If the respondent gives her/his consent, the interviewer provides a consent document that has to be filled out by the respondent her/himself. This document records the respondent's SHARE identification number, Social Security number (SSN), and information used to generate and/or check the SSN. Most importantly, linkage is only possible with the respondent's signature. The signed document then is directly sent to the DRV.

The DRV collects the consent letters and creates a data set from all SHARE respondents who consented to the linkage. In Germany, the SSN always is generated in the same way and includes date of birth, the first character of the (birth) name, and a gender code. Therefore, with the help of additional information collected on the consent form, it is possible to check whether the SSN is correct, to correct it if necessary, or to generate it if the respondent gave consent but couldn't provide the SSN.[2]

After the end of fieldwork, the DRV creates a file that consists of the respondents' SHARE identification numbers and SSNs. Based on this information, the DRV is able to identify the respondents' records in their database in order to create a scientific use file. For data protection reasons, the SSN is deleted from the database after the file is generated.

The scientific use file is sent to SHARE and linked with the SHARE data using the SHARE identification number. Mismatches can be identified by comparing demographics such as gender and year and month of birth, which are included in the scientific use file as well as in the SHARE survey data. The project of linking administrative data from the DRV already started in wave 3 by linking administrative information to respondents´ self-reported life histories (SHARELIFE).

BIOMARKERS IN SHARE

One recent development in social surveys is the inclusion of physical measurements and biomarkers. So far, these measurements often have been taken in smaller nonrepresentative clinical studies. In the last

[2] In contrast to the U.S., in Germany, the Social Security number is not so commonly used; nearly no one knows her/his number by heart. Additionally, not every person in Germany has a Social Security number. People who were never subject to social insurance contributions (e.g., because they are civil servants) are not included in the database. In 2009, the DRV held accounts for about 66 million Germans, thus covering about 80% of the population.

couple of years, more and more large-scale surveys added physical measurements and biomarkers to their programme since there is promising scientific value to it:

(1) **Measurement of respondent health can be improved.** Standard health questions in surveys often are subject to the respondent's own interpretation (of the question), own evaluation or perception (of health status), and own knowledge (of health status). The value of subjective health measurements is undeniable, but some research questions require objective measurements. Biomarkers enable researchers to validate respondent self-reports and therefore study the amount and determinants of under-, over-, and misreporting in large-scale population surveys.
(2) **Identification of causal relationships.** Biomarkers can help to understand the complex relationships between social status and health and their physiological pathways.
(3) **Pre-disease information.** Biomarkers allow the identification of pre-disease pathways, since the physiological processes are often below the individual's threshold of perception.

A unique feature of SHARE is that it builds on existing European surveys by incorporating a wider array of assessments that include multiple measures of self-rated health, specific chronic and acute diseases, symptoms, multiple measures of disability and functioning, mental health, cognitive function, and objective measures of performance (grip strength, walking speed, chair stand, and peak-flow). From the first wave on, SHARE combined self-reports on health with two physical performance measurements: grip strength and walking speed. Additionally, respondents reported their height and weight. In wave 2, SHARE added peak-flow and chair stand to the questionnaire programme. In wave 3 (SHARELIFE), grip strength was the only physical measurement included. Currently, wave 4 data is being collected, this time including grip strength, peak-flow, and self-reported height and weight.

Wave 4 also adds biomarkers to the German part of the study. Measures included are height (in addition to respondent self-reported height), waist circumference, and blood pressure. Additionally, SHARE Germany collects blood for dried blood spots (DBS), which will be analyzed in a laboratory with regard to total cholesterol, HbA1c, and C-reactive protein (CRP). The results from the lab then will be linked to the SHARE data set. In summer 2010, SHARE Germany conducted a small wave 4 pretest (125 interviews; 86 individuals agreed to DBS sampling) to test the protocols and logistics of the biomarker collection as well as the collaboration with the lab analyzing HbA1c and CRP and testing a method for cardiovascular disease estimation (total cholesterol vs. ApoA1/ApoB). An overview of the health measures in SHARE can be found in the table on the following page.

The ethics review board in Germany advised to provide respondents with the results of the blood spot analyses via their GPs if requested. This adds further logistics to the project since respondents have to provide their GPs' addresses and special letters for the GPs had to be designed. Furthermore, respondents have the option to narrow the range of possible analyses with their blood (e.g., exclusion of DNA analyses).

While the linkage of survey data and biomarkers is relatively new for Germany, experience from other countries with respect to such linkage has been extremely positive (e.g., Crimmins & Seeman, 2001; Weinstein & Willis, 2001). A similar pretest is planned for France in wave 5 with funds from a large French public organization. Denmark is preparing for the collection of biomarkers in wave 5 as well. We expect to combine all these efforts towards a full-scale implementation of biomarker collection in wave 6 (2014–2015).

Overview of Physical Measurements & Biomarkers in SHARE

	Wave 1 (2004/05)	Wave 2 (2006/07)	Wave 3 (2008/09)	Wave 4 (2010/11)
PERFORMANCE MEASURES				
Grip strength	yes	yes	yes	yes
Lung strength (peak flow)	—	yes	—	yes
Walking speed	yes	yes	—	—
Chair stand	—	yes	—	—
BIOMARKERS (Germany only)				
Height:				
Self-reported	—	—	—	yes*
Measured	—	—	—	yes
Waist circumference	—	—	—	yes
Blood pressure (seated)	—	—	—	yes
BLOOD BIOMARKERS (DBS) (Germany only)				
HbA1c	—	—	—	yes
C-reactive protein	—	—	—	yes
Total cholesterol	—	—	—	Method still
ApoA1/ApoB	—	—	—	to be decided

*In all countries.

CHALLENGES & OPPORTUNITIES

So far this pilot project—which combines survey data, biomarkers, and administrative data—is taking place in Germany only.[3] The expansion of linking administrative data and biomarkers over more SHARE countries is planned for future waves (subject to funding).

Researchers who want to link administrative data to survey data have to answer four essential questions first:

1. Which organisations are responsible for storing administrative data on pension contributions and payments? On which level are they stored (e.g., national, regional)?
2. Is the access to individual administrative data on pension contributions and payments legally possible for researchers?
3. Is the linkage of individual administrative data on pension contributions and payments with survey data legally possible? Are there any special requirements regarding the ethical review in case of linkage?
4. What are the conditions under which researchers are given access to linked data? Is access given across borders?

Collecting and linking record data within one country is already a challenge, but it becomes even more challenging when linkage is done in several countries and still expected to produce comparable data, since each country has different regulations, data sources, and formats, which in the end all have to be combined in a harmonized survey. It has to be ensured that data formats and contents are as comparable as possible, although full comparability will never be achieved since data sources differ to a very large extent. Privacy legislation poses another challenge: data dissemination rules often cannot follow the standards set by the survey to which the administrative data are linked. But restricted access to linked data will make cross-

[3] Administrative data also has been successfully linked to SHARE survey data in Denmark, but no biomarkers have been collected as of this writing.

national analyses using linked data a very difficult enterprise. Thus, new cross-national solutions of data access that fulfill all legal confidentiality requirements are needed.

The collection of biomarkers is not less challenging in a multinational setting. Here, the essential questions are as follows:

1. What are the conditions (e.g., written consent) under which blood samples can be obtained from respondents in each country?
2. Are there any special requirements regarding the ethical review in case of collection of biomarkers?
3. Are trained interviewers allowed to take blood samples if minimally invasive methods (e.g., dried blood spots) are used?
4. Can blood samples be sent across borders for analysis?
5. Is access of researchers to biomarker data subject to specific conditions?

SHARE is still investigating the specific requirements and limitations of collecting biomarkers across Europe— and in some countries, breaking new ground—since the collection of biomarkers is far beyond usual survey business.

The scientific value of collecting biomarkers and linking administrative data to representative survey data is undeniable, especially with regard to aging research, but it also offers great opportunities for methodological experiments and research. To get access to respondents' administrative data records, respondents need to provide their Social Security number. Asking for this (in some countries together with written consent to link the data) may have adverse affects on retention and response rates. The same holds for the collection of biomarkers, which increases respondent burden and may affect the willingness of survey participants to cooperate in future waves. To shed more light on this issue of nonresponse, SHARE is conducting some fascinating experiments:

- All German SHARE respondents who participated in previous waves were asked for their Social Security number and for their participation in collecting biomarkers. Since these are panel respondents, we already have a great variety of information about them, which allows us to study determinants of nonresponse.
- Wave 4 adds a large refresher sample to the study in Germany. Since not all respondents from the refresher sample will be asked to participate in administrative data linkage and biomarker collection, we are able to compare those who participated with those who were not asked in order to identify potential biases caused by the introduction of record linkage and biomarkers.
- SHARE also is experimenting with different incentives. We will examine the effect of unconditional monetary incentives on respondents' willingness to participate in the study. Respondents from the refresher sample will be randomly selected into three different treatment groups and a control group. Each treatment group will receive a different amount of money (either 10, 20, or 40 Euros) in advance together with a cover letter introducing the SHARE study. The control group receives a cover letter only (no monetary incentive).[4] This experiment will allow researchers to evaluate whether monetary incentives contribute to increasing participation rates in general, but it will be particularly interesting to examine the effect of incentives on participation rates with regard to collecting biomarkers and linking administrative data.

[4] This incentive experiment will not take place in sampling units with less than 10,000 inhabitants.

- Collecting biomarkers and asking for SSNs is way beyond usual survey business—especially for interviewers. Not all interviewers feel comfortable about such an enterprise. Hence, interviewer effects also might play an important role. Although interviewers are the key to success of a survey, often not much is known about interviewers' attitudes towards the research projects and their motives for working as an interviewer. Therefore, we asked all German SHARE interviewers to participate in a paper-and-pencil study, the aim of which is to learn more about the interviewers themselves. In particular, we are interested in the work experience they have, which strategies they apply to cope with refusals, and how they feel about the collection of biomarkers and the linkage of administrative data to find out how this affects their success in collecting the respective information.

As already pointed out, so far Germany is the only country to combine the four data sources:

1. Information on current living conditions from waves 1, 2, and 4 of SHARE
2. Retrospective life histories from wave 3 (SHARELIFE)
3. Administrative process data from the DRV
4. Objectively measured biomarkers

We expect the fieldwork for wave 4 to be finished in early fall 2011. Although we are still in an early stage of fieldwork, preliminary results look very promising. After the end of the fieldwork, we will process and link the colleted data and release it to the research community, and we will evaluate the processes, logistics, and protocols to refine them for wave 5 if necessary. Detailed debriefing sessions with our interviewers will help us identify problematic issues.

SHARE is looking toward an interesting future. More and more countries join the SHARE family, and many of these will introduce the linkage of pension fund data and the collection of biomarkers and explore the possibilities to link other process data (e.g., health insurance data) to SHARE.

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The National Health Interview Survey Redesign and Other Upcoming Changes

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A BRIEF DESCRIPTION OF TODAY'S NATIONAL HEALTH INTERVIEW SURVEY

The National Health Interview Survey (NHIS) went into the field for the first time in July 1957. From the beginning, the survey was designed to represent the U.S. civilian noninstitutionalized population and serve a diverse community rather than focus solely on selected policy or program needs. Topics presently covered by the relatively stable core of the survey include health status, utilization of health care services, health insurance coverage, health-related behaviors (such as use of tobacco and alcohol), risk factors, and demographic and socioeconomic information. In addition, supplemental questions on special topics are added to the NHIS questionnaire each year, co-sponsored by government agencies other than NCHS.

The most recent extensive revision of the NHIS questionnaire was in 1997. Since then, the NHIS has collected data about all family members in the Family Section of the NHIS core, from one randomly selected adult (the "sample adult") in the Sample Adult Section, and about one randomly selected child (the "sample child") in the Sample Child Section. To improve precision of estimates for certain minority subpopulations, the NHIS has been oversampling Black persons since 1985 and Hispanic persons since 1995. Also, since the NHIS sample was last redesigned in 2006, Asian persons have been oversampled, and the probability of selection as the sample adult has been increased for persons age ≥65 who are Hispanic, Black, or Asian.

The NHIS is in the field collecting data in face-to-face interviews virtually continuously throughout the year. Telephone follow-up sometimes is done to finish parts of the interview. The questionnaire is administered in either English or Spanish. The Census Bureau has been NCHS's contractor for fielding the NHIS since the inception of the survey. Each year, NCHS releases one year of NHIS microdata online in public use files that have been suitably altered to protect confidentiality. In recent years, this data release has occurred less than six months after the end of the data collection year. Paradata describing the NHIS interview process are released along with the annual public use files, and multiply imputed income and earnings data are released about two months after the annual microdata release.

NHIS staff members analyze NHIS data and produce a variety of publications and presentations. In particular, the NHIS Early Release Program produces two quarterly reports (on 15 key indicators and on health insurance coverage), and one biannual report (on cell phone usage). To provide early access to microdata by outside analysts, the Early Release Program also produces periodic preliminary NHIS microdata files for use in the NCHS Research Data Center. The Early Release Program is so-named because its products are made available before the annual public use microdata files are released.

For more information about the NHIS, see www.cdc.gov/nchs/nhis.htm

For a list of NHIS supplements and their cosponsors, see www.cdc.gov/nchs/nhis/supplements_cosponsors.htm

For more information about the NHIS Early Release Program, see www.cdc.gov/nchs/nhis/releases.htm

This paper describes two NHIS projects:

- Planning for and development of the next NHIS sample redesign
- Planning for and development of two systems for online real-time analysis of NHIS microdata

PLANNING FOR & DEVELOPMENT OF THE NEXT NHIS SAMPLE REDESIGN

The NHIS sample is redesigned about every 10 years, a few years after the decennial census. The most recent redesign was implemented in 2006. The next redesign is expected to be implemented in 2014 or 2015. In planning for that next redesign, NCHS must decide the characteristics of the next NHIS sample and whether to contract again with the Census Bureau or to contract with a private-sector survey research firm to field the survey. NCHS's Board of Scientific Counselors (BSC), which is the official advisory committee for NCHS, reviewed the NHIS program in 2008–2009, and one of the BSC recommendations was to consider the possibility of using a private research firm. (See www.cdc.gov/nchs/data/bsc/NHISFinalReportwithexecsumm112108.pdf)

To assist NCHS in planning the next NHIS redesign, an outside contractor is now developing descriptions and cost models for various potential modifications to the NHIS sample design. This also will assist NCHS in assessing the viability of using an outside private contractor to field the NHIS.

The current NHIS sample design uses an all-area sampling frame of housing units that were in place at the time of the 2000 Decennial Census. NHIS operates as a U.S. Code Title 15 survey, and as such, NHIS does not have access to the Census Master Address File (MAF). Therefore, NHIS must do its own listing of household addresses. Working for the NHIS, Census staff members go into areas designated by the Census Bureau and make lists of the addresses of households in those areas. The NHIS sample is drawn from those lists. Admittedly, the listing process is duplicative, but that is the tradeoff necessary for Title 15 surveys to have access to and control over the addresses of the households in their samples. NHIS also obtains information from building permits in order to be able to add new households to the sample.

As a Title 15 survey, NHIS may release sample addresses to its own contractors for additional data collection, which would not be permitted if NHIS were a Title 13 survey. For example, the Medical Expenditure Panel Survey (MEPS), conducted with the Agency for Healthcare Research and Quality (AHRQ), "piggybacks" on the NHIS interviewed sample by using half of the NHIS interviewed households as the MEPS sample frame. A private contractor fields MEPS, requiring addresses of NHIS-interviewed households to be given to the contractor. If NHIS were a Title 13 survey, those addresses could not be provided to an outside private contractor; MEPS would have to be fielded by the Census Bureau.

The NHIS has PSUs in all states and the District of Columbia. State-level estimates using NHIS data are representative of their respective states, but because of sample size limitations and depending on the specific estimates, some estimates may not have adequate precision to be useful. NCHS is able to release annual state-level estimates of health insurance coverage for the 20 largest states. By combining data from multiple NHIS years, more state-level estimates with adequate precision can often be produced. In its next redesign—sooner if possible—NCHS is hoping and planning to increase the NHIS sample size within specific states to add precision to estimates, and NCHS also wants to add PSUs to some states to add breadth of coverage. In the field now, the 2011 NHIS has an increased sample size within all but the 18 largest states. In its next redesign—sooner if possible—NCHS plans to add an address-based telephone component to the NHIS sample to further increase state-specific sample sizes. The questionnaire for the telephone component will necessarily have to be shorter, and the resulting data will be more complex to analyze, but there is a great and increasing demand from policy makers and other analysts for state-level NHIS estimates, and a telephone component will be a less costly (and more flexible) way to provide that capability.

Specifically, the outside contractor is developing cost models for the following hypothetical future NHIS designs:

- Basic designs
  - A design the same as the current NHIS sample design
  - Specific types of modifications of the current NHIS sample design
- Designs providing improved state estimates
  - With additional face-to-face interviews
  - With additional telephone interviews
- Designs collecting biomeasures (e.g., height, weight, blood spots, buccal cell swabs)
  - Using interviewers
  - Using specialists (such as technicians)
- A multipurpose NHIS sample design: one that deals with the tradeoffs between improving state estimates and collecting biomeasures and does some of each
- A design such that a survey like the current NHIS would serve as the sample frame for a survey like NCHS's current National Health and Nutrition Examination Survey (NHANES)

Once the reports are received from the outside contractor, NCHS will make some difficult decisions, such as whether and how to integrate NHIS with NHANES, what the next NHIS design will look like (if NHIS is not integrated with NHANES), what the next integrated design will look like (if NHIS and NHANES are integrated), and what contractual arrangements to make for fielding the future version of the NHIS.

In particular, an integrated NHIS and NHANES would be complex in many ways. Multiple contractors would likely be necessary. Protecting confidentiality of some NHIS respondents would be more difficult because some NHIS data would be linked to NHANES data, and NHANES is publicized in communities where the survey is being conducted, so as to increase response rates. Such publicity also puts the primary sampling units in the public domain. Also, the timeliness of releases of some NHIS data might be reduced because NHANES now releases its data every two years, and NHIS releases its data every year; thus, linked NHIS and NHANES microdata would have to be released using the less frequent release timeframe. Analysis of the complex integrated data would be more complex, increasing analyst burden.

NHIS also must plan a necessary transition from using large amounts of listing to using the U.S. Postal Service's Delivery Sequence File and/or commercially-available address files. Research will be required to determine how best to use these address files to meet the specific needs of the NHIS, and it is hoped that listing will be reduced to a minimum and be confined to selected rural areas only.

Further, developing plans for a new sample design is a lengthy and costly process. NHIS planners must deal with perennial NCHS funding insufficiencies, uncertainties, unpredictability, and inconvenient timing as they move forward to implementation of the next design.

PLANNING FOR & DEVELOPMENT OF TWO SYSTEMS FOR ONLINE REAL-TIME ANALYSIS OF NHIS MICRODATA

Users of the National Health Interview Survey have several resources for accessing its microdata and analytic products. Users interested in a particular health subject or in health survey methods can consult appropriate reports and papers produced by NCHS analysts and by many others outside NCHS. Those who wish to conduct their own NHIS analyses can use the online NHIS public use microdata files, which are released once per year, along with thorough documentation, and are available free of charge. NHIS data

users also can analyze the preliminary NHIS microdata files (described above) that are made available in the NCHS Research Data Center (RDC) before the annual public release. Further, they can use microdata from the Integrated Health Interview Series (IHIS), which is a collection of selected NHIS variables that have been "harmonized" to facilitate time-trend analysis from the 1960s to the present. IHIS microdata are based on NHIS public use files and are available free of charge from the IHIS Web site at www.ihis.us/ihis/. The IHIS project provides extensive documentation and now has a tabulation capability. NHIS users whose analyses require access to restricted NHIS (or other NCHS) variables that are not released publically can use the NCHS RDC, which provides on-site access facilities in Hyattsville, Maryland; in Atlanta; and at Census Bureau RDCs across the country. The NCHS RDC also provides a capability for remote analysis of restricted variables. Analyses conducted via these RDCs are limited and carefully supervised to protect confidentiality. RDC users must submit and have approved a project proposal, and fees are charged. See www.cdc.gov/rdc/ for more details about the NCHS RDC.

To provide additional mechanisms for analyzing NHIS data, NCHS is developing two online real-time analytic systems that will be publicly available without submission of project proposals and without charge:

- ***System P*** will provide analyses of the same **public use** NHIS microdata files that are released online each year.
- ***System R*** will provide analyses of public use NHIS microdata plus selected **restricted** variables, with a focus on state-specific analyses. (The NHIS currently does not release state identifiers on its public use files.) Analyses will not be "canned" but will be performed in real time "on demand" from the user but with strict screening for disclosure avoidance before provision of the analyses.

These two new systems will complement the mechanisms and opportunities already available for access to NHIS data and analyses. Many surveys already offer analytic capabilities like System P. However, capabilities like System R are very rare because of the complexity of real-time confidentiality screening for analyses, which is an ongoing area of research.

The development of System R is motivated by the great and increasing demand for state-level analysis. Because health care is largely administered at the state level in the United States, state-level analysis is needed for research and for development and evaluation of health policies. In particular, monitoring the effects of the new Patient Protection and Affordable Care Act will require state-level analyses.

System P and System R will provide assorted analyses (fewer for System R because of disclosure avoidance requirements). The analytic "wish list" includes descriptive statistics, outlier identification, multi-way cross tabs, significance tests, standard errors, confidence intervals, assorted graphs (scatter plots, bar graphs, histograms, box plots, time trend graphs, U.S. maps displaying estimates by state, graphs able to show results for very large sample sizes effectively, etc.), crude rates, directly-standardized rates (using selected standard populations or user-provided standard populations), regressions, etc. These analytic capabilities will be implemented in stages.

System P and System R both will use methods for variance estimation that account for the complex sample design of the NHIS. Both systems will use NHIS microdata dating back to 1997 (when major changes to the NHIS questionnaire were made), and both will add newly available NHIS microdata each year.

For System R, proper confidentiality screening is the most critical requirement. Analyses must be screened to avoid disclosure before the results are shown to the user. Screening methods must be rigorous and sophisticated to meet the strict confidentiality mandates for NCHS data. A cocktail of methods will be used, some involving alteration of the underlying NHIS microdata files and some involving real-time data

perturbation and barriers to certain analyses. Special methods will be used to prevent "differencing attacks," in which malicious data users try to gain information about inappropriately small groups of individuals by subtracting frequencies in one cross-tabulation from frequencies in another.

Confidentiality screening methods for System R must take into account the separate public availability of microdata from NHIS public use microdata files and linked files. NHIS has imposed nontrivial restrictions on System R that will require it to use confidentiality screening methods that will not alter or impose any concomitant new restrictions on the contents of public use NHIS microdata files or reduce the excellent timeliness with which those public use files are released.

NCHS staff members are working closely with an outside contractor on the following phases of the project to develop System R and System P:

- **Phase 1:** Develop, describe, and demonstrate the effectiveness of methods for screening analyses produced by System R that are sufficiently rigorous to meet NCHS's high standards for disclosure avoidance and confidentiality.
- **Phase 2:**
  - Develop and demonstrate System R. Produce appropriate documentation for use by those maintaining the system and those using the system. Include instructions for adding new capabilities and/or data to the system.
  - Develop and demonstrate System P. Produce appropriate documentation for use by those maintaining the system and those using the system. Include instructions for adding new capabilities and/or data to the system.
  - Delivery of System R and P may be carried out simultaneously.
- **Phase 3:** Install and implement the new systems at NCHS.
- **Phase 4:** Maintain the new systems and update them as new data and analytic capabilities are added.

The methods developed in Phase 1 must be acceptable to NCHS for the development of System R to continue to later phases of that project.

Many challenges will be encountered in developing System P and System R. For example, once ready for public use, both systems will have to undergo a series of approvals to ensure that system security is protected. Especially in the case of System R, this may take some time.

Development of disclosure avoidance methods for System R is one of the biggest challenges. Such methods are being custom developed for System R to meet NCHS's strict confidentiality requirements. They must balance confidentiality needs with the need for the analyses to be sufficiently accurate and useful after disclosure avoidance techniques are applied. Further, they must be effective, but a system that very often refuses to let see users see requested analyses would be frustrating to users. Before going online, System R will have to be approved by the NCHS Disclosure Review Board.

Obtaining adequate funding for development and maintenance of the two systems is another challenge, given the uncertainties and limitations of the federal budget and of NCHS's budget. These uncertainties apply not just to amounts of funding but also to the timing of when funding will become available. For example, augmentation of a survey's sample size requires advance planning (e.g., for sample design modification, hiring extra interviewers, and training new interviewers), and commitments sometimes have to be made before funding has been confirmed.

CONCLUDING REMARKS

The National Center for Health Statistics is the nation's official health statistics agency, and the NCHS National Health Interview Survey is the primary source of information on the health of the civilian noninstitutionalized population of the U.S. NCHS strives to meet the needs of its data users and thus to promote public health through providing valuable data and data products. NCHS is committed to conducting the NHIS and meeting the challenges of developing plans for the survey's future, including developing its next sample design and developing new user services such as online real-time analytic systems.

SESSION 4 DISCUSSION

Linda Dimitropoulos (RTI International)

Research using health data is entering an exciting period where we will increasingly seek to supplement primary data collection through surveys with various other types of data linking electronic data sets in new ways to answer complex research questions. Supplementing survey data with other types of data is not new, but the sheer volume of electronic data that has been collected to date and that is growing at a rapid pace will change the way social scientists and health researchers work. For example, linking data sets, especially those with medical records or images, can lead to extremely large data sets that can run into 100s of terabytes or even a petabyte of data. Data sets of this size create challenges for those charged with the management and analysis of the data. This trend will create the need for specialists who are expert in the management and analysis of extreme data sets. This wealth of data will create both opportunities and challenges that will change the way we think about and use health data going forward.

The health data sets of the future will draw from many sources. They will include data collected for research purposes through traditional survey data collection methods and data collected for many other purposes, such as administrative data and electronic medical record data. Health researchers will come to rely more heavily on linking to administrative records, all-payer claims data, electronic medical record data, and other types of data collected for purposes other than research. There will be more access to clinical data sets originally collected for purposes of patient care through electronic health records and personal health records, health data generated by individuals through the use of Web and Smartphone applications, and data collected through social media such as Twitter and Facebook and from Web sites such as www.PatientsLikeMe.com. As the availability of electronic data sets becomes greater, so do the challenges of making sure that the data are appropriate and of sufficient quality for research purposes. Understanding the genesis of the data will be critical to assess the validity of the data. Those collected for purposes other than research may not have been collected with the rigor necessary to support the conclusions that health researchers need to draw. Researchers also will need to assess the appropriateness of the data to answer a given research question. For example, electronic prescription data can tell us if a drug has been prescribed, the pharmacy claims data can tell us if the prescription was paid for, pharmacy data can tell us if the prescription was picked up, the patient can tell us if he or she took the medication, and a lab test result can validate whether the patient self-report is accurate.

This was an insightful set of papers that point to both exciting times now and in the future of health research, but they also point to a number of exciting challenges ahead. Each paper stretched our thinking about what is possible and identified some of the challenges and solutions we will face. The Schaan and Korbmacher and the Von Korff papers discussed innovative ways to answer complex questions by linking data sources and data types in innovative ways.

The Schaan and Korbmacher discussion of plans to link data collected by the Survey of Health, Ageing and Retirement in Europe (SHARE), a panel survey that provides an important source of data for policy analysis and research in Europe, to administrative records highlighted many of the challenges inherent in linking data sets from multiple sources. The study is conducted cooperatively among 18 countries and serves to create a rich source of cross-cultural data. However, SHARE recently decided to attempt to link to administrative data sets and add physiological measures to the data collection protocol. Linking to administrative data is seen as a way to validate the survey data, to reduce bias, and to decrease respondent burden, but there are specific challenges that health researchers need to address to ensure that the effort

results in a quality data set that is appropriate for addressing the research questions. The first challenge is determining what the law will require in terms of variables available for matching and whether the goal is to match records based on the personal identifiers or match records using a measure of statistical similarity. The process the SHARE project followed of obtaining consent to link to the records and having a specific scientific data set prepared is a familiar process to most researchers dealing in identifiable data, and it is never straightforward. The real challenge comes when SHARE expands this approach to the other countries. They will need to identify comparable administrative data sets in the partner countries, if they exist; navigate the legal and ethical issues of linking the data, if it is permitted; and determine whether the authority for granting permission is at the local, regional, or national level. The issues of sharing health data in the U.S. mirror these challenges in many ways. There are both state and federal laws governing the use of identifiable health information, and each organization holding a given data set offers a different set of criteria that need to be met through some type of data use agreement. Data quality and consistency will be added issues, especially with administrative data and other data that are collected for purposes other than research.

The Von Korff paper also discussed the potential for data linkage to create valuable data sets that bring together clinical information collected for treatment purposes, administrative data from payer claims, genetic information from saliva and blood samples, and primary data collection to create data sets that may be valuable for certain types of population health research. The data discussed in the paper comes from many sources, including 15 health plans and research centers and about 370 providers. Data quality questions were not discussed, but there are a number of questions that should be addressed. The question that comes to mind regarding clinical data is how much variation is there in the types of electronic health records used by providers to capture the information? Different systems have differing formats and collect data in different ways. What kind of variability is there across health plans in how they collect genetic information and biomarker data? How are the records matched? These should be critical questions for researchers linking to these potentially rich sources of data.

The additional three papers focused on data quality and consistency. The Willson paper acknowledged the increasing use of administrative data in health research and the need to evaluate the quality of these data. Willson demonstrated that cognitive interviewing can be used to evaluate administrative data quality by interviewing the staff that collects birth certificate data to learn more about the process and to identify ways to improve the quality of basic birth record data. Reliance on administrative data to validate survey data and to reduce recall bias assumes a level of quality that may not be warranted. Willson identified many sources of variation in the ways these seemingly simple data are collected—staff interpreting the federal standards differently, hospitals varying in their policies on how the forms should be completed, and missing information derived by the staff using various methods to impute the data all affect data quality.

The Klabunde, McLeod, and Willis paper focused on identifying ways to improve survey data collection among physicians. Physicians are an important source of data for understanding trends in knowledge, practices, adoption and use of new technology, and, importantly for NCI, progress toward physician-related goals for reducing cancer burden. Physicians are also a challenging group to sample, recruit, and interview for a number of reasons. This paper discusses a number of key issues including the need for a reliable method of sampling physicians, citing that the American Medical Association Masterfile is out of date and that there is no reliable way of sampling physicians working within organizations. Sampling issues aside, it is increasingly difficult to contact physicians because of the layers of office staff that insulate them. The study noted that over time, phone surveys have given way to mail surveys and that there is variable success with Web-based surveys. Identifying appropriate incentives is also a challenge and often fails to take into

account the office staff that is key to getting access to physicians. Klabunde recommended that the federal government find a solution to the sampling frame issue. The Centers for Medicare and Medicaid Services requires physicians to have a national provider identification number to receive payment under the Medicare program, which might serve as a starting point. It would not include providers that do not participate in the program, however.

The National Health Interview Survey (NHIS) undergoes a sample redesign every 10 years. For this redesign, the goals include improving the state estimates and adding the collection of biomeasures. Redesigning the NHIS is rife with challenges and requires careful consideration of the options before committing to a course of action. The concerns are driven by the need to ensure the quality of the data. The redesign of the NHIS discussion by Gentleman described how NCHS is weighing its options in an effort to preserve the quality of the data collected, given the challenges of uncertain funding for research and the need for the federal government to identify ways to reduce the federal budget. There is no doubt that in the future we will need to look for ways to streamline survey data collection at the national level and look to existing data sources to fill the gaps.

The data sets of tomorrow will be larger and more complicated and will allow researchers to answer questions they might not have been able to answer just 10 or 15 years ago. The sheer volume of electronic health data that has been collected to date and that is seemingly growing exponentially will change the way we think about and conduct health survey research.

SESSION 4 SUMMARY

Angela Jaszczak (NORC) and **Nancy Walczak** (Lewin Group)

Looking to the future, data sets used by health survey researchers for population-based health and policy research likely will consist of multiple different types of data from a wide range of sources. These potentially include survey responses drawn from a variety of different methods, biomarkers or biomeasures and related health information, and administrative data linked from public and private data repositories. The diversity of future data and sources is noted in the omission of the word "survey" from the title of this session. A number of new national-level initiatives, some publicly funded and some proprietary, that are aimed at promoting the development and adoption of electronic medical records (EMR) and all-payer claims databases point to a new and potentially beneficial role for electronic health data in future population-based health research. In particular, the health data sets of tomorrow will be more robust and have the potential to link data to create family/household histories and to support longitudinal research.

BASIC THEMES IN THE FLOOR DISCUSSION: EXPANSION OF ELECTRONIC HEALTH DATA IS CREATING NEW OPPORTUNITIES & CHALLENGES

Three basic themes were identified and discussed in the floor discussion: new challenges and opportunities, using existing methods in new circumstances, and ensuring the provenance of the data is appropriate for its purpose.

The Expansion of Electronic Health Data Are Creating New Challenges & Opportunities

All papers presented provide new information on the challenges and opportunities that exist today when working with multiple data sources and types of data.

Challenges:

- **Response rates:** What does this mean when the context is not a survey?
- **Linkages:** Informed consent, HIPAA.
- **Harmonizing data:** Are items across data sets, across countries, comparable?
- **Evaluating quality of available data:** Cognitive methods may be appropriate.
- **Quality assurance:** For data we have not collected ourselves.
- **Appropriate for use:** Data are reliable when recorded for a specific use (e.g., date of birth/death)

Opportunities:

- Getting more robust data for multivariate analysis.
- Efficiencies of scale, both in time and cost.
- Getting more timely data, not relying on recall.
- Technological innovation will dramatically reduce costs associated with primary data acquisition
- Can create standing orders to collect supplemental or missing information.

Taking What We Know & Applying It to the New Circumstances to Advance the Practice

Another theme that surfaced in the papers and floor discussion was how to take already established methods and apply them to the data sets of tomorrow to improve validity and confidence in the conclusions

drawn from them. For example, the paper by Willson applied established cognitive interviewing techniques to understand the process of creating a birth record. The floor discussion raised the issue that the Birth Information Collectors are trained to provide birth certificate data rather than additional research items. This is reflected in the variability of the research data items.

The paper by Klabunde, McLeod, and Willis challenged the group to take what methodologists know about physician surveys and think about their similarities to establishment surveys to better reflect the realities and evolving structure of medical practices and care settings in today's world. Among the questions raised: Can some other members of an organization answer some questions, or do they have to be physician-answered? Sampling frames are problematic—the AMA Masterfile is frequently out of date. Also, we should rethink the use of incentives and who should receive them, and we need more research to the barriers to conducting research in physician practices.

In addition, as health data sets and surveys expand to include multiple data sources, health survey researchers should implement traditional experiments and review past work by colleagues in their efforts to grow the data sets. For example, there is current research on data set linkages that might serve as a resource for future work.

Notably, the NHIS was mentioned in nearly every session of the Tenth Conference, and its upcoming redesign was discussed at length in this session. The NHIS often is considered our "gold standard" for survey data collection. Consequently, there was an extended discussion precipitated by the presentation of the NHIS redesign and other upcoming changes. Two major changes were made to the initial structure of the NHIS in 1997: (1) The instrument changed from paper-and-pencil to CAPI, and (2) The questionnaire itself was revamped in major ways. The NHIS sample was redesigned to its current form a few years later and implemented in 2006. The launch of the next redesigned survey is targeted for 2014–15. Discussion of the NHIS raised interest in integrating NHIS with NHANES and the lessons learned from the earlier integration with the MEPS. NHIS has been faithful to limiting household sample participation to two surveys per year. Hence, integration is limited by sample use. Development costs and sample size expansion continue to challenge the survey. Can the use of existing data sources—e.g., electronic health records—be considered in the future to augment data collected by the in-person interview?

The discussion of the Schaan paper focused on data linkage, informed consent, and the use of biomeasures to validate available data. These are issues that we will face in the United States as we move forward in collaborating with electronic health data aggregators. The author shared with us that administrative data are not 100% complete and also described the techniques used to encrypt the data to maintain privacy.

Purpose & Provenance

A final theme and guiding principle running through the session was the importance of understanding the purpose and provenance of the data. For example, what was the original intended use of the administrative data? What insures the quality of the data? When data are used for billing purposes, they are subject to audits for correct coding and patient identification. They are not designed for health research, so potentially "imputed" information such as income and race/ethnicity that may be on the record must be qualified. For example, the pension data presented in the Schaan research is self-validated because German citizens are naturally incented to verify its accuracy and completeness so that their pension credits are accumulated properly. Other variables on the record may not be self-validating. For example, laboratory data that survey researchers often think of as objective may be improperly transcribed or calibrated due to

human error within the laboratory setting. We must be mindful that we understand the original intent of the data and are extrapolating cautiously and insure that the data we use are "fit for use."

FUTURE RESEARCH

While there is an extensive body of work based on the NHIS, research using the robust HMORN data assets is just beginning to emerge. Von Korff described how widespread implementation of electronic health data systems by health plans and providers—e.g., electronic medical records, health claim records, and other health IT—has the potential to transform health research in the future. He shared how researchers at the HMORN consortium supplement data collected via traditional methods such as computer-assisted telephone interviewing or mail surveys through linkages to health plan data stored in a virtual data warehouse. The floor discussion inquired about access to the data by the research community at large. Currently, the HMORN and member organizations are collaborating with numerous researchers, but independent access to their information and data sets by third parties it not permitted.

RUNNING DIALOGUE

The papers presented on physician surveys and the NHIS redesign stimulated a running dialogue that focused on the role of maintaining high response rates. In regards to this session, if the health data sets of tomorrow are combined from multiple sources, we will need to consider new metrics other than response rate for researchers and journal editors to use in order to evaluate the reliability and generalizability of conclusions drawn from the data sources. It was posed to the group that instead of asking "What was the response rate in the study?" should we be asking "Where did the data come from, and is this an appropriate use of the data?" Towards the end of the session, there was recognition that the real issue is demonstrating lack of nonresponse bias; response rate is simply an imperfect proxy.

CONCLUSION

Survey methods must keep pace with the developments in health information technology. Through enhanced techniques for accessing and linking records maintained by medical establishments and improvements in collecting biomeasures and environmental samples, the health data sets of tomorrow can be more robust and more current. While there are gaps and limitations in all data sets, the papers in this panel discussed some of the innovative ways that the emerging health information infrastructure is being used to inform health care decisions at the patient care and policy levels.

SESSION 5: Potential for Innovations with New Technology and Communication Tools

ORGANIZERS: David Dutwin (SSRS/Social Science Research Solutions), and
Richard Kulka (Abt Associates)
CHAIR: David Dutwin

The Social Media Opportunity in Health Research

Reg Baker, **Theo Downes-Le Guin**, and **Erica Ruyle** (Market Strategies International)

INTRODUCTION

As in the research industry as a whole, the model for federal health research over the last century has been one that relies heavily on designing surveys and asking questions. Over about the last five years, the emergence of interactive information-sharing technologies (commonly called Web 2.0) and social media applications has created the opportunity for several new approaches to research. These new approaches are focused on observing or listening to people talk about their health and health issues in spontaneous conversations on social networking sites rather than drawing subjects into structured surveys and asking them questions. Our paper argues that although this type of research is not likely to replace surveys any time soon, it might help us improve survey design and even yield insights that may be difficult to uncover with traditional survey methods. We overview the three principal types of social media research now being practiced and describe some ways health survey researchers might use them in their work.

SOCIAL MEDIA OVERVIEW

Kaplan and Haenlein (2010) define social media as "a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, which allows the creation and exchange of User Generated Content" (p. 61). To put it another way, social media is a family of Web sites on which people can share information and experiences with people they know or do not know. Sometimes those sites are so-called "walled gardens," such as Facebook, where participants have control over with whom they interact and who has access to content they post. Other sites, such as blogs and forums, are public or semi-public (accessible with a password, but once accessed, all content is discoverable), and users can post their own content and comment on or simply read content posted by others. Although some private sites include one-to-one chat features, content sharing on social media sites is mostly asynchronous and can be about anything and everything. All sites, whether public or private, have varying Terms of Use that govern participant privacy and appropriate use of posted information and content. These Terms can present both technical and ethical restrictions on the aggregation and use of content by third parties. Nevertheless, the ability to capture and analyze the content on social networking sites is at the heart of social media's allure for researchers.

The growth of social networking sites and the popularity of social media has been *the* Internet story of the last five years. For example, the digital marketing firm Econsultancy (2011) reports the following: the professional networking site LinkedIn now has 100 million members; Twitter has over 175 million registered users; YouTube averages about 300 million visitors per month; and over 5 billion images have been posted to the photo sharing site Flickr. In one of the most oft-cited examples of social media's reach, enthusiasts point out that if Facebook with its 640 million members (Pi Social Media, 2011) were a country, it would be the third largest in the world after China and India. In the U.S., a recent Nielsen study (2010) estimated that among adult Internet users in May 2010, 21% had started a blog and 55% had established a profile on a social networking site, and they were spending an average of over six hours a month in social media. The same study estimated the unique U.S. audience for social media Web sites at 148 million people.

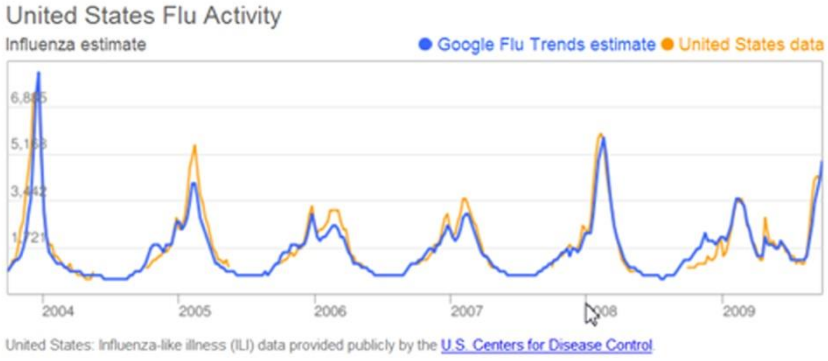
Skeptics might argue that these numbers are not what they seem, that there is certain amount of hype in some and that a closer look at their measurement methodologies raises legitimate questions about their accuracy. Nonetheless, it is hard to argue against the rapid and widespread growth of social media of all

kinds. A more important criticism for anyone interested in using social media content as a research source is something called The 1% Rule (Arthur, 2006). Also known as the 90:9:1 principle, this rule of thumb states that only about 1% of social media users are highly engaged and post content; another 9% are moderately engaged and may comment on, modify, or forward someone else's content; and the remaining 90% are observers (or, more commonly and disparagingly, lurkers) who are passive participants reading what others post.

This general murkiness of universe counts and extent of true participation in social media is troubling for researchers accustomed to doing probability-based research from high-quality sample frames. Nonetheless, social media research has a useful and important role to play in health research—not as a replacement methodology but as a complement to more traditional approaches. The model for research for the past century has been hierarchical, with researchers asking questions in a way that, despite the appearance of give-and-take, creates a one-way flow of information. With the advent and spread of social media, answers to questions sometimes exist before we articulate or ask those questions, and information flows are rarely one way. In the social media context, the researcher's role shifts away from a position of control to being just another person who observes, has questions, and sometimes participates in discussions but with a slightly different objective. The metaphor for this model of research is frequently characterized as a shift from asking to listening, to hearing, and to conversing; while this metaphor is often characterized as new and groundbreaking, some researchers might recognize the basic tenets as an adaptation of ethnographic principles to online and social media communities.

Google Flu Trends is a useful example of how new Internet-based methods can exist alongside traditional data collection methods. The figure below shows an aggregation of Google search data about flu over a six-year period. It compares the volume of those searches with CDC estimates of the prevalence of diseases with flu-like symptoms. The correspondence between searches and flu prevalence is quite remarkable. The Google data are produced in real time, while the CDC data come with a lag. The CDC data no doubt are more accurate, but the Google data are an excellent leading indicator. Like social media research, Google Flu Trends employs data generated by a large (and in this case unconnected) group of online users to create a value for the researcher that is separate and distinct from the users' objective. Although not social media research *per se*, it is a good example of how Internet methodologies can coexist with if not enhance health research using traditional methods.

Figure. Sample Graph from Google Flu Trends†



†Downloaded from www.google.org/flutrends/about/how.html on May 2, 2011.

The graph plots counts of Google searches about flu and CDC estimates of the prevalence of diseases with flu-like symptoms. Both measures show significant increases in late 2003, early 2005, late 2005 through early 2006, late 2006 and early 2007, early 2008, and from the early fall of 2008 until about March of 2009.

METHODS

As the popularity of online social networks grows, the likelihood that "organic" user-generated content relevant to our research goals grows as well. Nevertheless, the Internet does not provide an idyllic land of readily available research content. Leveraging online content generated in social media presents three challenges. The first is that we cannot always be present in all of the online discussions we might like to research; the Internet never closes, and content creation occurs constantly and across the world. The second is that the topics of interest to us as researchers may not be generating as much online content as we would like or need; while people are talking, they may not be talking about our exact interests. And finally, even when those topics of interest are being discussed, the content generated by users may be superficial or not quite on mark for our research needs. Fortunately, there are methods and emerging best practices to address all three of these issues.

Social Media Monitoring

- The first method and most easily accessible form of social media research is the automated monitoring of online conversations about health-related issues in such naturally occurring online communities as social networking sites, blogs, microblogs, forums, and chat rooms. Google Alerts represents a basic but very common method for this type of monitoring; dozens of Web-based software tools known colloquially as "screen scrapers" allow the researcher to identify, aggregate, and analyze content containing relevant keywords from a wide variety of social media sites. More sophisticated platforms allow researchers to modify the basic search topics with related topics, as well as add retrospective date filters and domain filters. Content then can be analyzed using machine-learning or natural language processing software capable of identifying broader themes and, to a limited degree, even automating coding of slang, jargon, and irony. This software also can help researchers understand the context of discussions, code it based on positive or negative sentiment, and analyze key trends.
- The first step in social media monitoring is to decide on a set of key search terms that define the relevant content to be searched for and aggregated along with the time period during which the monitoring will be active. The second step is to identify the types of online sources or even specific sources to be targeted by the search. As noted above, these target sources mostly will be public sites such as blogs, online forums, media sites, microblogs, open communities, and even semi-private sites (such as Facebook) where permission has been given. Depending on the topic, the researcher may choose not to monitor some sites (such as mainstream media sites) because they already are only reporting on online conversations and are not really part of the dialogue. Even this exclusion is far from perfect since corporate (news release, Web site) and media (news site, editorial) content can be widely repeated and adapted in "consumer conversation" sites such as forums. Furthermore, mainstream media may be tagged as blogs or personal blogs depending on the content. At the analysis stage, text processing and content analysis software charts the frequency, location, and context where the search terms occur and attempts to assign a positive or negative sentiment to each. While incredibly sophisticated compared to even a few years ago, monitoring platforms are viewed by most as still in their technical infancy. Sentiment coding and thematic analyses, in particular, can be error prone and misleading depending on the content (Wright, 2009). Currently, sarcasm and other linguistic nuances can trip up these platforms and lead to incorrect sentiment coding.

- As an example, for this paper, we engaged with a social media monitoring service to monitor conversations that include the term "health care reform." The search specifically excluded mainstream media sites; however, no other filters or adjustments were added, creating what could be most generously described as a broad, unrefined monitoring process. Over a 12-month period from April 2010 through March of 2011, the service returned about 275,000 pieces of content. Roughly half of that content came from blogs, with the remainder from online forums (17%), microblogs (14%), social networks (10%), and news sites (7%). In terms of specific Web sites, the top three sources were Twitter, Facebook, and the site for *The Hill*, a Washington-based online newspaper focused on the U.S. Congress. We conducted a sentiment analysis that showed net positive sentiment until August/ September of 2010, followed by negative sentiment up until the November elections and then a period of up-and-down instability. In terms of specifics, the positive context for "health care reform" included phases such as "reduce cost," "save money," "good thing," "finest hour," protect benefit," and "improve care." Negative sentiment included phrases such as "repeal healthcare," "worsen shortage," "not help Democrat," "hurt Nevada," and "hurt economy."
- Were this a "real" study, these initial results might cause us to do additional filtering of the sources we targeted for inclusion, since the negative sentiment in particular seems to have an overemphasis on the political implications of the health care debate. More importantly, despite starting our analysis with an impressive 275,000 pieces of content, the software is only able to categorize less than 1% of it accurately enough for us to report it with confidence. Further exploration of themes and affect would require us to extract partial text of the content identified by the monitoring platform, export that content into a more capable and unstructured text analysis application, and devote considerable skilled resources to drawing further meaning from the content. We believe this search demonstrates both the potential of social media monitoring as a research method as well as the weaknesses of current software tools.

One such real study was done by Schillewaert and colleagues (2010). For their study, they selected 20 Web sites that serve as forums where people with epilepsy and their caregivers can engage in spontaneous online conversation about the disease. The researchers aggregated the content from these sites and looked at the topics people discussed, the frequency of those topics, the sentiment and emotions that people have around them, and the natural language patients and caregivers use when talking about seizures. The study results have many uses. A key one for survey researchers is the need to carefully consider questionnaire wording so interviewing is a more natural process that uses words and terminology to which epileptics can easily relate.

Netnography

A second method takes advantage of existing, naturally occurring online communities to understand a topic in more detail than may be possible with other methods. Netnography, a termed coined by Kozinets (2010), is a form of ethnography that adopts ethnographic methodologies to online. It is a technique in which the researcher integrates into an existing community focused on a specific topic to learn about linguistic conventions, motivations, and behaviors. Netnography is an inherently natural, unobtrusive way to study social groups, eliciting deeply genuine and candid opinions on any given topic and observing group interactions and behaviors as they take place. It capitalizes on the multidimensional nature of the online experience to collect large amounts of information in less time than traditional ethnographies or surveys.

The first step in a netnography study is to locate and join an appropriate existing community or communities. The netnographer settles in to understand how the community functions and what topics members typically discuss. By carefully observing and participating in the community, the netnographer

builds rapport and trust, making it acceptable to ask direct research-related questions. Through field notes, entrenched experience, and a deep understanding of the online community, the netnographer emerges from the field with rich observations and data. Not only does the netnographer pay attention to social relations within the community but also to the connections among communities as well. In addition, just like an ethnographer would pay attention to surroundings, the netnographer pays close attention to the layout of the communities in question and uses that information to glean deeper insight.

Analysis typically takes place throughout data collection in order to build on insights gained while in the field. After the fieldwork is complete, all data are triangulated to understand the "native" point of view and the meaning it has for the larger research issues. Netnography not only answers specific research questions but also reveals new insights by following the natural flow of communication, sharing, and group interactions.

A potential opportunity in health studies might be an online community of sufferers of the same disease. For example, the Web site www.patientslikeme.com offers a forum where people suffering from any one of several chronic diseases discuss their symptoms, diagnoses, therapies, side effects, and the challenges of living with the disease.. Community members regularly update their profiles to note their conditions, the drugs they are taking, and the quality of their lives. The site includes tools that make it possible to plot this information over time. A netnographer might join the community, announce his or her presence, and describe the research being undertaken. By observing over time the interaction among members and the information they share, the netnographer gains insight into the patient journey—that is, the sequence of experiences from the onset of symptoms through diagnosis, treatment, side effects, and learning to live with the disease. In the process, the netnographer comes to understand more clearly how people talk about the disease with one another and the sorts of questions that might be acceptable to ask to draw out thoughts and feelings that otherwise might stay hidden.

Online Community

A third method makes it possible to study in detail topics that do not generate enough content on public sites to drive meaningful analysis. This method relies on an artificial community created by the researcher rather than a naturally occurring community of the sort used in monitoring and netnography. It is a more proactive (and in a sense, traditional research) approach in which the researcher recruits individuals to join an online community created for the specific purpose of engaging them on one or more research topics. The researcher stimulates conversation within the community and prompts and listens while members give direct feedback or interact and discuss issues amongst themselves. In some ways, this type of community is like a focus group but with a good deal more interaction between and among community members and over an extended period of time. Software tools have eased the burden of recruiting members, managing the interaction, and reporting results.

Creating and then maintaining an effective online research community requires first and foremost an authentic reason for the community to exist. A community can be centered around a shared experience such as a disease, a brand that people love or hate, a topic of strong shared interest like video games, or just a hobby. No form of community—whether private and built for researchers or public and organic—can survive for long if community members don't get something positive, engaging, or cathartic out of the ongoing experience. In some instances, monetary incentives can sustain a short-term community, but just as in the physical world, social engagement with like-minded individuals is a more compelling and enduring basis for a community.

Online communities are built using software platforms that allow for all the bells and whistles of today's social media experience—a compelling home page or wall, group discussions, private discussions, private moderator-to-participant interactions, multimedia posting, profiles and avatars, private online groups, polls and surveys, and co-creation sites including document sharing. The look and feel of communities is often modeled after dominant social media sites like Facebook to provide an easy user experience. Members can be recruited in any number of ways, both online and offline. Communities can last anywhere from a couple of weeks to years and involve anywhere from a couple of dozen people to thousands. Regardless of size, many communities are subject to the 1% Rule, so the community moderator(s) must work at engaging everyone through such devices as asking members to confirm the ideas that active participants have put forth.

Once established, long-term communities should take on a life of their own. A successful community may be heavily moderated, but if lively and vital, it also will generate content and insights from direct participant interaction. It's important to create constant reasons for people to visit the community—fresh questions, ideas, product previews, and so on. Longer-term communities also will suffer attrition over time, so ongoing recruiting and growth is a key part of maintenance on top of moderation.

A focused, short, small community is not unlike a focus group at the analysis stage. It produces a good deal of raw material in the form of transcripts and short survey results along with the researcher's own memory of the types and tenor of interactions. The research synthesizes this down to key findings and insights just as with a traditional focus group. A longer-term larger community may end up looking more like a broad social media monitoring engagement in that it can generate a large amount of content for analysis. In this instance, the researcher may fall back on the same sort of text processing and sentiment coding analytic tools that are typically used for monitoring.

CONCLUSIONS

In this paper, we have argued that social media analysis has long-term potential for health research. We also have described the three most popular social media research methods, all of which continue to develop as does the social media framework itself. Social media monitoring can combine quantitative and qualitative findings to provide leading indicators of health-related trends. Online communities and netnography are potential replacements/complements for traditional qualitative methods that help us explore issues in greater depth. All are good tools for understanding health experiences over time. In some instances, they may help provide access to otherwise hard-to-reach respondents.

While each of these methods may offer some opportunity for quantitative style analysis and reporting, they are primarily qualitative techniques. Issues of coverage and data quality limit their utility for many types of public sector quantitative research. Thus, the principal value of social media research methods at this point in their evolution would seem to be the potential to deepen our understanding of how patients and providers experience health issues so that we can design better surveys or to complement survey results as a way to yield more compelling insights.

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Social Media, New Technologies, and the Future of Health Survey Research

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This is an interesting time to conduct health surveys. The majority of our work to produce accurate and current statistical information on health conditions, behaviors, and attitudes continues to be done using telephone, mail, in-person, and "traditional" Web survey techniques. Meanwhile, outside the realm of survey research, much of the world has moved on to faster, newer, and more flexible means of communication. Mobile technologies and social media platforms have outstripped more traditional communication vehicles, outgrowing or supplanting, for example, old-style telephones, radio, and newsprint. For example, Facebook, the largest and most popular "social media" site, has over 500 million registered users as of July 2010 (Facebook, 2011) and is now being used by 51% of all Americans age 12 and over (51%), as compared to only 8% in 2008 (Webster, 2011).

For many reasons, it is increasingly difficult to efficiently collect high-quality health survey data with the "old" data collection methods. However, the "new" communication vehicles and platforms present both promise and pitfalls as means by which to supplement, if not supplant, health survey data. It is, indeed, an interesting time to conduct health surveys—and it is time to consider the role of new technologies and social media in the future of health survey research.

TRADITIONAL METHODS IN TODAY'S SURVEY ENVIRONMENT

By now, virtually everyone in the survey research industry knows that response rates are in decline. Scholars in the survey research field have been decrying that decline since at least the 1990s (de Heer, 1999; Steeh, Kirgis, Cannon, & DeWitt, 2001; Tortora, 2004; Curtin, Presser, & Singer, 2005). Nonetheless, the majority of major health surveys today are still conducted using traditional survey research techniques, protocols, and modes. For example, most health survey data today are collected via in-person, telephone, or mail surveys, or through a Web survey formatted with the desktop user in mind. However, because of declining response rates for these traditional modes and protocols, the validity of the data collected in such a manner is increasingly suspect. One of the major concerns with traditional data collection modes is the threat of nonresponse bias. The inability to reach respondents makes securing their response less likely and more costly. Although the relationship between response rate and nonresponse bias is not straightforward, the threat of nonresponse bias can increase when response rates decrease if the reason for nonresponse is correlated with the key survey estimates (Groves, 2006). In addition, for better or worse, response rates are sometimes seen, in the absence of other information, as a lone indication of quality. The Office of Management and Budget (OMB) requires that surveys with a response rate under 80% conduct a nonresponse bias analysis (OMB, 2006), which creates an additional concern for federally funded health surveys.

A variety of factors have been cited for declining response rates for health surveys, including increased mistrust in requests for data from both government and corporations and increased reluctance to share "personal data" with unknown persons or entities (e.g., Kim, Gerhenson, Glaser, & Smith, 2011). With the rise of telemarketing prior to the advent of the Do Not Call list early in the 21st century, Americans were inundated with calls that could be indiscernible at first from survey requests (Remington, 1992; Tourangeau, 2004). Junk mail and spam e-mail also were more prevalent than ever during this time (Kim, Jeong, Kim, & So, 2010; Tynan, 2002). Technological advances, such as caller ID on both landlines and mobile phones, likely contribute to declining cooperation and response rates (Kempf & Remington, 2007). Furthermore, the threat of computer

viruses from unknown sources and news stories about identity theft and stolen laptops containing individuals' confidential information likely led to people becoming more protective of their personal information.

Challenges with nonresponse have not been limited to telephone surveys. In field surveys, controlled access housing units with features such as gates, guards, and buzzer systems make it harder for individuals to be contacted at their door thus producing higher rates of nonresponse (Cunningham et al., 2005). These impediments must be overcome to successfully complete field data collection operations (Keesling, 2008). Because individuals have restricted access in these ways, reaching them and collecting quality health survey data has become more difficult and more costly (Curtin, Presser, & Singer, 2005).

Another major issue facing health survey data collection is the reduction in landline telephone coverage (Blumberg & Luke, 2009). Surveys conducted by telephone, for example, run the risk of missing entire—but important—segments of the population of interest if the "traditional" landline-based telephone sampling methods are not conjoined with (or replaced by) a cell phone frame. This is an especially important consideration when conducting health surveys of young people or low-income adults, for which landline coverage is especially low. Holbrook, Green, and Krosnick (2003) suggest that telephone numbers can no longer be relied upon for survey sampling.

ENTER THE NEW TECHNOLOGIES

To contemplate how new communication modes might improve health survey data collection, understanding the nature of these systems is a prerequisite. Technologies that provide the most utility for survey research are usually those already common in everyday life. With the decline in coverage (and response) of traditional modes and the increase in coverage (and potential for response) with new modes, numerous possibilities exist, including text message surveys, multimedia survey invitations sent to cell phones, and surveys conducted through social networking sites. Paradoxically, while many people rely on technologies like caller ID to avoid being contacted and sharing information about themselves in surveys, they are simultaneously willing to share massive amounts of personal information on social networking sites. Any given Facebook newsfeed, Twitter posting, or blog entry is likely to include reports of an individual's mood, health status, dietary intake, and physical activity—exactly the kinds of health-related information that survey researchers try to collect. Many of the new communication modes are based on social networks, where individuals are connected as "friends" and share information, interests, and other methods of interaction, and, at the extreme, the information being shared on these platforms can be utilized with no survey interaction to answer health-related questions. At the least, we should consider the role that new technologies and social media, such as Facebook, Twitter, and Second Life, can play in supplementing traditional survey research methods: sampling, tracing, and pretesting activities like focus groups and cognitive interviews may benefit from new technologies.

Although there is a myriad of social networking systems available, we focus here on three diverse and popular systems: Facebook, Twitter, and Second Life. We summarize what these systems are, who uses them and how, emerging uses in survey research, and uses in adjacent fields that may be adapted for health survey research purposes.

Facebook

One of the most popular social networking services, Facebook is used to share information about oneself, such as hometown, current city, education, employment, interests, and favorites. Users can post photos, videos, notes, and status updates that are visible to other users. Facebook launched in February 2004

and currently has over 500 million users (Facebook, 2011). A *USA Today*/Gallup Poll conducted with an RDD sample of 1,487 adults in the U.S. found that Facebook is used by 43% of U.S. adults, but coverage is highest among young adults: 73% of 18–29 year olds, 55% of 30–49 year-olds, 33% of 50–64 year-olds, and 17% of those 65 and older. It is used by 58% of college graduates but only 28% of those with a high school degree or less. Of those with less than a $90,000 annual income, 41% use Facebook; 55% of those with an income over $90,000 use it (Morales, 2011).

Facebook is already being used for tracing respondents on surveys such as The National Longitudinal Study of Adolescent Health (Add Health) (Perkins, Granger, & Saleska, 2009) and the Longitudinal Studies of Child Abuse and Neglect (LONGSCAN) (Nwadiuko, Isbell, Zolotor, Hussey, & Kotch, 2011). The process for contacting panel members is not very different from searching telephone directories or change-of-address databases and reaching out by traditional means. To obtain information, a survey researcher sets up a Facebook page and searches for panel members using information such as name, location, and place of education. The researcher does not "friend" the respondent but instead simply attempts to make positive contact through Facebook's private messaging system. There may be ethical concerns with this approach as many view Facebook as a personal space, not to be violated by entities that are not personal acquaintances, but studies to date have shown modest success with this approach.

Facebook currently lacks a sampling frame, meaning representative samples of its user population may be infeasible at the moment. There have been efforts to compile and make available a frame of Facebook users (Boges, 2010), but the quality and completeness of such data would require extensive evaluation before claims of representation could be made. Some convenience sample surveys have been conducted on Facebook. For example, MyType (2011) conducts personality tests and opinion surveys and has administered 700,000 completed interviews to date through self-administered Web questionnaires on a third-party application within Facebook. Of those who have completed MyType surveys, 100,000 opted to publish their results on their personal Facebook pages. Contrary to the traditional thinking about surveys and confidentiality, some respondents may be motivated by the prospect of sharing their opinions with friends online. In fact, one study of undergraduates found that even among those with a high level of concern about privacy, most have joined online social networks (Acquisti & Gross, 2006). Part of the appeal of online social media is "empowering exhibitionism"—the ability to reveal aspects of one's personal life without shame (Koskela, 2004). It is a means of counteracting top-down vertical communication styles and rebelling against authoritarian sources of information. Also empowering is the ability to construct one's online identity through the choice of what to share, including activities, beliefs, locations, preferences, etc. (Albrechtslund, 2008).

Facebook also may have utility for pretest recruitment. Prior research has discussed the utility of online classified systems, such as Craigslist, for efficiently recruiting research subjects for pretesting activities such as cognitive interviews (Murphy et al., 2007), and Facebook, with its expanding reach, may allow for recruitment in similar ways. By advertising opportunities to participate in pretesting activities to individuals with selected demographic characteristics, users would have the opportunity to simply click on an ad and be put in touch with the survey organization.

The web of socially linked friends and acquaintances that comprise Facebook also lends itself well to registry building, which is an important activity in many health studies. For instance, the World Trade Center Health Registry aimed to contact approximately 400,000 individuals who were in the vicinity of the World Trade Center in New York City during the attacks of September 11, 2001, or during the cleanup operation (Murphy et al., 2007). Although a multifaceted approach was successful in compiling the registry (Pulliam, Dolan, & Dean, 2010), it is likely that much of this work could have been streamlined by allowing for respondent-driven sample generation through spreading the word on Facebook. There is, for example, a

Transplant Registry developed by the government of Malaysia on Facebook, and the (US) National Cord Blood Registry has over 15,000 "likes."

In the adjacent field of market research, social media platforms like Facebook are used to measure "buzz" about brands and to follow and track consumer behavior around the clock (Asberg, 2009; Jansen, 2009). One approach to tracking public opinion via Facebook is to analyze group wall posts using speech content analysis (Casteleyen, Mottart, & Rutten, 2009). In addition to content analysis of wall posts, market research data can be collected by engaging Facebook users in social media conversation. For example, engaging Facebook users with brands is best driven by encouraging a community of consumers that is focused around a particular brand (Smith, 2009).

Twitter

Twitter is another emerging source of data on people's health behaviors and attitudes. It is a widely used micro-blogging service, similar to the status update function of Facebook. Twitter users submit short messages ("tweets") of 140 characters or less. Tweets appear on the users' profile pages and the profiles of their followers. Most Twitter users tweet about personal life (72%), work life (62%), news (55%), and "humorous or philosophical observations" (54%) (Smith & Rainie, 2010). Fewer, but significant numbers, use Twitter to share photos (40%), videos (28%), or their location (24%).

Twitter launched in July 2006 and now has over 190 million users (Schonfeld, 2010). A 2010 survey of 2,257 adult Internet users that was conducted as part of The Pew Research Center's Internet and American Life Project revealed demographic characteristics of Twitter users. Twitter is used by 8% of U.S. adults who use the Internet and is used at a higher rate by women (10% of Internet users) than men (7% of Internet users). Among Internet users, Twitter is more likely to be used by young adults (14% of 18–29 year olds compared to 7% of 30–49 year olds), by African Americans (13%) and Latinos (18%), and by urban dwellers (11% compared to 8% suburban and 5% rural) (Smith & Rainie, 2010).

As opinion-rich data sources like Twitter grow in popularity, they can be used to actively seek out and understand public opinions. Opinion mining and sentiment analysis methods have been developed to address the computational treatment of opinion, sentiment, and subjectivity in such information sources (Pang & Lee, 2008). For instance, Chew and Eysenbach (2010) argued that while surveys are popular in measuring public perceptions in emergencies, they can be costly and time consuming. They illustrated an "infoveillance" approach that analyzed tweets using the terms "H1N1" and "swine flu" during the 2009 H1N1 pandemic. They conducted a content analysis of tweets and, through this process, validated Twitter as a real-time health-trend tracking tool. They found that while H1N1-related tweets were used primarily to disseminate information from credible sources, they were also a source of attitudinal data and experiences. The authors suggested that tweets can be used for real-time content monitoring and may help health authorities respond to public concerns.

Squiers et al. (2011) supplemented a survey of women age 40–74 with an analysis of social media posts around the time of the controversy surrounding the U.S. Preventive Services Task Force (USPSTF) revised breast cancer screening recommendations, developing a search syntax using keywords to identify relevant blog posts and tweets. They found that, by this measure of public sentiment, the majority of mentions related to the revised screening recommendations were either unsupportive or neutral about the new USPSTF guidelines. Although this study did not compare tweet content and survey results directly, it did demonstrate how the former can supplement the latter when investigating reactions to health guidelines.

From adjacent fields of survey research, we find examples of utilizing social media to predict election outcomes or match survey results. O'Connor and colleagues (2010) compared tweet sentiments with consumer confidence and political opinion, and while the results varied, they found correlations are as high as 80% for some comparisons. Tumasjan, Sprenger, Sandner, and Welpe (2010) found that the mere number of tweets mentioning a political party reflected the election result in the 2010 German federal election. More generally, a content analysis suggests that tweets can be used to measure political sentiment.

In addition to tracking trends and sentiments, Twitter can be used as a simple diary to track behaviors. TweetWhatYouEat.com allows users to document their meals and caloric consumption. Alex Ressi, who launched the Web site, suggests that tweeting is effective for improving behaviors because it adds a "component of shame" by documenting behaviors and making them publicly available (Heussner, 2009). Qwitter is a similar concept to TweetWhatYouEat. Launched in 2008 by Tobacco Free Florida, Qwitter users tweet the number of cigarettes they smoke each day and view graphs of their use over time as they try to quit (Heussner, 2009).

Researchers could benefit in several ways from conducting studies using Twitter diary methods. If the sample members were already active Twitter users, respondents would presumably enjoy tweeting and would be accustomed to using this method of reporting information about themselves. Thus, response rates might be higher and responses more candid. Twitter responses would probably be less retrospective and more accurate than paper-and-pencil diary responses because respondents could be prompted about how they are feeling or what they are doing at a particular moment. Other advantages include access to timestamp data for all entries, instant data transmission to researchers, and reduced equipment and training costs. Twitter diaries would not be without limitation, however. Researchers would be limited by the capabilities of Twitter, including the 140 character limit. In addition, because Twitter might not be novel to respondents, it is possible that they would be more likely to forget to update their diary for the study. However, this could be compensated for by having the researchers prompt users with reminder tweets.

Second Life

Advances in technology in recent years have introduced additional possibilities of survey modes and methods of administration. One of the more futuristic possibilities is conducting interviews with embodied conversational agents (ECAs), which are graphical depictions of humans that can interact with respondents in human-like ways. Though this method is feasible, it is rarely used for survey interviews because, as ECAs become more human-like, they become vulnerable to human-like social influence, like social desirability effects (Cassell & Miller, 2008).

Second Life (SL) is an online three-dimensional environment in which users ("residents") create avatars through which they interact with the virtual world. SL residents are able to communicate via instant messaging and voice chat, but compared with other social networking technologies, the purpose of SL is more for entertainment than communication with persons known in real life. Unlike Facebook and Twitter, which generally are used to augment one's real-life persona and relationships, SL users represent themselves in ways that may be a complete departure from their real-life appearance and personality.

SL launched in 2003; that year, 50,000 user hours were logged in-world. User hours peaked at 481 million in 2009, and declined by 10% in 2010. Residents in Second Life come from more than 100 countries; about 40% of SL avatars are from the United States. In November 2008, the most active users were 25–44 years old (64% of hours logged) and male (59% of hours logged) (Linden Lab, 2009).

Epidemiology was one of the first fields to start conducting research in virtual worlds. Since research shows that people with avatars in virtual worlds tend to consider the avatar as part of their identity (Taylor, 2002), virtual worlds can provide a realm to understand people's disease response behaviors. The outbreak of the World of Warcraft "corrupted blood" virus validated and inspired the use of virtual worlds for epidemiologic modeling (Balicer, 2007; Lofgren & Fefferman, 2007). Epidemics have broken out in virtual worlds, and remarkably, avatar behavior in response to these virtual epidemics has been similar to human behavior in real life epidemics: they try to avoid the infected. For this reason, Second Life is a useful tool for modeling epidemics like HIV/AIDS (Gordon, Björklund, Smith, & Blyden, 2009).

Preliminary research indicates that Second Life may provide a context-rich environment for conducting cognitive interviews (Dean, Cook, Keating, & Murphy, 2009; Murphy, Dean, Cook, & Keating, 2010). Advantages of both text-based chat and voice chat could be harnessed. With a text-based chat, full transcripts of cognitive interviews could be generated. Using voice chat, respondents' emotive cues could be captured. The only element from an in-person cognitive interview that would be missing would be the facial and physical expressions, although Second Life users can manipulate these for their avatars to a certain extent. An additional advantage of cognitive interviews in Second Life is the efficiency with which avatar respondents are recruited in the virtual world (Dean et al., 2009).

And the Rest…

Other systems and technologies are being harnessed for health and survey research purposes, too. Numerous fields adjacent to health survey methodology have begun developing methods for analyzing data from social media and other new communication technologies. Epidemiologists, in particular, are beginning to use social media and Internet search behavior to identify and respond to disease outbreaks. A study of the 2008 flu season found that Google search trends mapped to flu outbreak patterns (Corley, Mikler, Cook, & Singh, 2009; Corley, Cook, Mikler, & Singh, 2010).

In addition to simply blogging or sharing videos and pictures about what they are doing, social networkers can share their current location by using GPS-based services, such as Foursquare. Foursquare users "check-in" at their real-life location using a Foursquare application on a mobile device (most often, a cell phone). Users receive updates of their friends' locations, receive tips about locations and discounts at participating stores, unlock badges identifying them as having met particular check-in milestones, and aim to become the "mayor" of a location by checking in to that location more than anyone else.

It is worth noting that social network platforms increasingly are being accessed on mobile devices. The percentage of Americans who can access the Internet using smart phones and other mobile devices is expected to grow from 39% in 2010 to 59% in 2014, according to a study by Yahoo this year. Also by 2014, more people will access the Internet on mobile devices than on desktop PCs, according to a study by Morgan Stanley. Survey researchers have been experimenting with handheld devices well before they became as ubiquitous as they are now (Peytchev & Hill, 2009).

EXPLORING NEW POSSIBILITIES WITH CREATIVITY & CAUTION

Our discipline aims to produce the most valid and accurate health estimates given the available resources. Social media platforms and other new technologies offer opportunities to achieve this goal in new ways and with more efficiency, but, in the rush to reap the benefits of these technologies and introduce new survey modes, we need to be cautious so as not to inadvertently decrease the quality of the health data being produced. This attention to quality must consider multiple perspectives. In the context of total survey

error, we need to consider the impact of methods on sampling error (sampling scheme, sample size, estimator choice) and nonsampling error (specification, nonresponse, frame, measurement, data processing) (Biemer, 2011).

Ethical considerations for any type of health survey research also need to be considered when a new mode is being evaluated. In our zeal to adopt and use new communications technologies and platforms, we must be prudent and circumspect in thinking about research ethics as applied to these new venues. Informed consent, of course, is a basic tenet of scientific research on human populations, and, in survey research, we are continually cognizant of the need to offer both privacy and confidentiality with regard to data offered by sample members.

Whether a researcher can "mine" or "scrape" data from social media sites like Facebook or other Web 2.0 applications like Second Life without obtaining *a priori* informed consent is a thorny issue, not yet resolved. In practice, obtaining informed consent, especially for passive research methods, is nigh impossible. And, even if one were able to obtain informed consent, doing so might well change the behavior of the individuals being observed, thus spoiling the effort.

Nowadays, virtually all Web sites and social media platforms include a "privacy statement"—many of which note that "data" posted on the site may be collected and analyzed in aggregate. Facebook's privacy statement, for example, has seen intense scrutiny for its changing nature and less-than-transparent approach to protecting user privacy. Facebook produces revenue by selling aggregate data to advertisers who can then better target market segments based on "likes" and the like.

WHERE DO WE GO FROM HERE?

We see the trend towards increased adoption of new technologies and forms of communication holding promise for the future of survey research. These technologies could supplement traditional survey modes to encourage participation from respondents who may well have a high level of comfort with new technologies. Using several and varied new-technology approaches may increase participation since people may appreciate the ability to choose their preferred response mode (Dillman, 2000; Schaefer & Dillman, 1998).

At present, there are more questions than answers concerning the best methods for utilizing new technologies and social media for health survey research methods. We intend to investigate several of these issues, as described in the table on the following page.

As a next step in our research, we plan to address some of these questions head on, conducting studies to advance the knowledge of new technologies and how they may impact health surveys. Specifically, we plan to evaluate the effectiveness of techniques to trace, recruit, or sample respondents using resources such as Facebook; conduct virtual cognitive interviews in Second Life; explore focus group and diary methods that take advantage of the interactive opinion-sharing nature of Twitter; pilot test a mobile micro-survey application that samples respondents based on their current geolocation; and evaluate the potential to supplement health survey research information with secondary analysis of data from sources such as Twitter and Internet search statistics.

Although new technologies and platforms—new ways of communicating—may not ultimately replace traditional approaches, it is critical that we evaluate the potential of new technologies and social media tools and their role in health survey research to stay current during a time of fast-paced evolution in communications. This is vitally important because by the time we conclude the current research, even newer technologies will be presenting additional opportunities and concerns. Constant monitoring is something

that may soon be feasible, and we must address the fact that surveys are a form of surveillance (Marx, 2008). This is an interesting time for health surveys; the future will be fascinating.

Questions for Investigation

QUALITY ISSUES	ADJACENCIES	COMMUNICATION PREFERENCES	REPRESENTATIVENESS
• Looking at the entire framework of total survey error, what data quality issues must we examine when considering survey work in these new technologies? • How reliable & valid are data collected through these platforms? • Furthermore, what tools & techniques are needed to be able to assess reliability & validity in these modes?	• What additional research is being done on these new technologies in adjacent fields, such as marketing, media studies, health communications, & human-computer interaction? • How can health survey researchers learn & benefit from this research?	• What can or will survey respondents share with survey researchers via these new tools, & how can we best tailor the request for this information? Since most social media communication is two-way or interactive, will survey researchers be expected to share information "back"? • How can we best make use of the interactive nature of many of these systems without sacrificing confidentiality or raising other concerns? • What information can we "share back" that attracts or motivates respondents and reduces survey error? • What modes of communication do different types of survey respondents prefer when being contacted for or when completing a survey? • Is there a difference between what respondents say they prefer & what methods they use to respond?	• What are the demographic profiles of users of different systems or technologies, & how do users differ from benchmarks? • Can frame data be compiled & representative samples drawn?

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The Feasibility of Using Handheld Computers to Conduct the Global Adult Tobacco Survey

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INTRODUCTION

Electronic Data Capture (EDC) methodologies to conduct surveys has are now frequently used in developed countries. Computer laptops have been used for many years to conduct in-person household surveys, and using handheld computers has become more common as well. The advantages of using computer-assisted interviewing (CAI) methods over paper-and-pencil interviewing (PAPI) have been well documented in the survey research field (see Weeks [1992] for an overview).

It is less common for CAI surveys to be conducted in developing countries, and using handheld computers is even less frequent. There have been recent published studies about using handheld computers for survey data collection in developing countries—Yu et al. (2009) describe a field test study in Fiji of 120 participants to evaluate the development of a handheld survey vs. PAPI; Bernabe-Ortiz et al. (2008) conducted a similar evaluation of a handheld survey vs. PAPI using 200 participants in Lima, Peru; Shirima et al. (2007) used handheld computers to collect survey data from over 21,000 rural households in southern Tanzania; Seebregts et al. (2009) report on using handheld computers in South Africa for over 90,000 interviews in seven separate studies; and Gupta (1996) used handheld computers in Bombay, India, to conduct a tobacco survey of over 99,000 persons. All of these studies had similar conclusions—using handheld computers was a feasible and successful methodology for collecting field data in developing countries. Note that these studies were not at a national level and were designed for sub- or specific populations.

The Global Adult Tobacco Survey (GATS) provides an opportunity to implement nationally representative household surveys in low- and middle-income countries using handheld computers for data collection. The development of GATS started in 2007 and the first phase of GATS was conducted between 2008 and 2010 in 14 countries: Bangladesh, Brazil, China, Egypt, India, Mexico, Philippines, Russian Federation, Thailand, Turkey, Ukraine, Uruguay, and Vietnam.

This paper provides an overview of the initial implementation of GATS in these 14 countries while assessing the feasibility of using handheld computers in low- and middle-income countries to conduct national surveys.

METHODOLOGY

Overview of GATS

The Global Adult Tobacco Survey (GATS), a component of the Global Tobacco Surveillance System (GTSS, www.cdc.gov/tobacco/global/gtss/index.htm), is a global standard for systematically monitoring adult tobacco use and tracking key tobacco control indicators. GATS is a nationally representative household survey of adults, 15 years of age or older, using a standard core questionnaire, sample design, and data collection and management procedures that have been reviewed and approved by international

experts. GATS is intended to enhance the capacity of countries to design, implement, and evaluate tobacco control interventions.

GATS uses a geographically clustered, multistage sampling methodology. First, a country is divided into Primary Sampling Units, segments within these Primary Sampling Units, and households within the segments. Then, a random sample of households is selected to participate in GATS.

At each address in the sample, field interviewers administer the Household Questionnaire (HQ) to one adult who resides in the household. The Household Questionnaire determines if the selected household meets GATS eligibility requirements and rosters all eligible members of the household. Then one individual (15 years of age or older) is randomly selected to complete the Individual Questionnaire (IQ). The Individual Questionnaire includes core questions about background characteristics; tobacco smoking; smokeless tobacco use; cessation; secondhand smoke exposure; economics; media; and knowledge, attitudes, and perceptions about tobacco. Participating countries may add and/or adapt questions to the GATS Core Questionnaire (Global Adult Tobacco Survey Collaborative Group, 2010) related to their country-specific situation. Once finalized, the country-adapted questionnaire is translated into local languages, as applicable before the survey administration.

GATS uses standard best practices such as pretesting questionnaires; reviewing survey proposals; technical assistance and training on data collection and management; conducting workshops and orientations; and providing consultation and technical feedback on data analysis and reporting. The GATS Comprehensive Standard Protocol (CSP) contains a series of standardized manuals. (The CSP can be accessed at the CDC's Web site: http://apps.nccd.cdc.gov/gtssdata/Ancillary/Documentation.aspx?SUID=4&DOCT=1)

GATS is conducted by each participating country by a consortium of partners. Typically the national statistical organization will conduct the data collection while the Ministry of Health and other in-country partners provide support in design and analysis. Technical consultation and review is provided by various GATS partners including the U.S. Centers for Disease Control and Prevention (CDC), the World Health Organization (WHO), Johns Hopkins Bloomberg School of Public Health (JHBSPH), RTI International, and the University of North Carolina Gillings School of Public Health (UNCSPH). Funding is provided by Bloomberg Philanthropies through the CDC Foundation.

Handheld Computers

GATS was initially developed as a paper and pencil survey. However, during development, GATS partners conducted a thorough evaluation of the use of EDC and concluded the use of CAI devices for GATS was not only feasible but also highly recommended. Available hardware and software was evaluated for incorporating into GATS based on ease of implementation and use at the in-country field level. Additional factors such as the ability to standardize both the data collection and data analysis process were also considered during the evaluation. Based on recommendations, handheld computers—specifically Hewlett Packard (HP) iPAQ©[1] devices—were selected for GATS implementation. RTI International provided technical support in developing their General Survey System (GSS) software for GATS.

[1] Use of "Hewlett-Packard (HP) iPAQ" is for identification only and does not imply endorsement by any of the GATS collaborating organizations.

General Survey System (GSS) Software

The GSS is a suite of software tools developed to facilitate the administration, collection, and management of survey data on handheld computers, specifically a Microsoft Windows©[2]-based platform running Windows Mobile 5.0 or Mobile 6.0, often called Pocket PC systems. The software system is designed to support field data collection activities where field interviewers collect data using handheld computers. The systems have been developed and tested using Hewlett Packard (HP) iPAQ Pocket PC systems. The software consists of six main programs, each dedicated to a specific function:

- **CMS:** a case management system that allows users to manage the case load on the Pocket PC.
- **GSS Engine:** a questionnaire development and presentation system engine that allows defining of data collection forms on a standard desktop PC and execution of these data collection forms or questionnaires on the Pocket PC.
- **Xmit:** a data transmission program that allows bidirectional movement of data, program updates, and control information to and from the Pocket PC over dialup, wireless, or wired Ethernet.
- **Developer's Tool Set:** a developer's menu system that organizes the access to the PC-based components of GSS.
- **Designer:** a questionnaire design program that provides a visual interface for preparing and/or modifying a survey instrument. The Designer allows the creation, deletion, and modification of questions in two languages at a time in the GSS.
- **Project Web site:** a Web-based suite of tools that facilitates survey management, survey monitoring, and reporting, and brokers the data transmissions to and from the Pocket PC to back-end database servers.

Three of the major programs—CMS, GSS, and Xmit—run on the Microsoft Windows Mobile-based handheld that the field interviewer uses, and the Developer's Tools Set runs on a Microsoft Windows-based laptop or desktop PC. The Project Web site runs on a centralized desktop or laptop Microsoft IIS Web Server running ASP.net Web pages linked to a Microsoft SQL Server database for data storage.

RESULTS

Implementation of Handheld Computers

As implementation of GATS started in the initial 14 countries, GATS partners confirmed the anticipated disparity of expertise and experience with using CAI methods. A few countries had experience with CAI surveys, sometimes specifically with handhelds. For example, Thailand and Brazil did their own programming of the GATS questionnaire using their own survey software (not GSS) for handheld computers. On the other hand, for some countries (e.g., Bangladesh), GATS represented the first national survey to be conducted by the country using an electronic mode of data collection. Thus, the amount of experience and expertise dictated the required level of training and support the GATS partners gave to each country. Implementation assistance included questionnaire programming, consultation on data management plans, and training of country IT and data management staff.

[2] Use of "Microsoft Windows" and "Windows Mobile" is for identification only and does not imply endorsement by any of the GATS collaborating organizations.

Questionnaire Programming

Once the countries adapted the GATS Core Questionnaire for their specific needs, the country-specific questionnaires were programmed for use on the handheld computer. A core questionnaire program was modified for each country's specific questionnaire. This included the addition of questions or entire sections, the deletion of questions or entire sections, and adapted question categories and response categories. The amount and complexity of adaptations varied by country.

In planning for GATS implementation, the expectation was that GATS partners would program the country-specific questionnaires for the pretest and then provide training to countries. The hope was that countries would then be able to make the changes to the questionnaire program for the main survey. However, in most instances, GATS partners ended up programming for the main survey as well. The reason was a combination of two issues: 1) countries' need for further training and/or experience, and 2) a lack of time or resources at the country level.

An important challenge was programming and setting up the handhelds for use with languages other than English. Most of the iPAQs were purchased by the CDC Foundation in the United States and sent to the countries for use in GATS. Since the operating system was in English, it was necessary to obtain and load external language packs that provided the character set and keyboards for the given languages. Often times, non-western characters required additional visual adjustments for the handheld screens including font size and text direction (e.g., right to left for Arabic).

Another challenge of using handhelds was the screen size (5 inches for iPAQ). It was important to design the questionnaire program and CMS given the limitations of space. While this was not a major issue for GATS, this could potentially be a limitation for other types of surveys.

Data Management Implementation

The GATS Data Management Implementation Plan (DMIP) manual (Global Adult Tobacco Survey Collaborative Group, 2010) provides a description of the procedures, practices, and resource information for GATS data management activities inclusive of data extraction, format, transfer, and aggregation, and chain of custody from the field interviewer to PSU/regions to the country level national data center (NDC). The DMIP outlines three models of data management:

- **Full Network—Web Model.** Fully networked model provides a Web-based system used for all of the following: case assignment via network upload and download, survey monitoring, upload of field data, and survey monitoring reports.
- **Partial Network—Some Field Phone/Internet Connectivity.** Includes the following: in-country system hosts consolidated database at the NDC, case assignment performed by memory card, interviewers export questionnaire data to memory cards, field supervisors or regional supervisors collect cards and upload data to the NDC, NDC combines files across PSUs/Regions.
- **Card-Based.** Includes the following: in-country system hosts consolidated database at NDC, case assignment performed by memory card, interviewers export questionnaire data to memory cards, NDC combines files from iPAQ-level files.

GATS partners worked closely with each country to design a data management plan that was appropriate given the country's infrastructure, expertise, and experience. Country infrastructure included internet coverage and access, as well urbanicity/ruralness. On one end of the spectrum, data management was conducted by manually gathering memory cards from each interviewer (on a regular basis) in order to collect interview data during data collection. On the other end, data management was conducted via the

internet where interview data was transmitted by field interviewers on a nightly basis (which is often done in the US and other developed countries).

Training and Technical Support

An overarching goal of GATS is not only to provide technical support but also provide capacity building to participating GATS countries. Capacity building related to electronic data collection is provided in two ways: 1) in-depth IT and data management training for both software and hardware, and 2) purchasing the iPAQs for the countries to keep. The goal is for countries to be able to conduct GATS again in the future and conduct other surveys using the software and hardware.

As part of a country's pretest training and preparation, an in-country IT/data management training workshop occurred where all IT preparations for the pretest were finalized, including the set-up of iPAQ handhelds. In addition, another in-country IT/data management training workshop was conducted prior to the main survey where country staff were provided additional in-depth training on the GSS PC software. In addition, GATS partners provided ongoing technical support throughout the entire implementation of GATS.

Outcomes

GATS was successfully conducted using handheld computers in all of the initial 14 countries. Twelve of these countries conducted GATS using the GATS GSS software while two countries (Brazil and Thailand) conducted GATS using their own survey software.

In the 14 initial GATS countries, there were approximately 250,000 completed GATS individual surveys using almost 3,000 handheld computers. The GATS questionnaire was programmed in nearly 40 languages. The hardware failure rate was less than 1%, even though the survey was often conducted in poor environmental conditions such as high altitudes, freezing temperatures, dry heat, high humidity, and monsoon seasons. The electronic data collection system used in GATS resulted in an almost 0% data loss.

The implementation of a range of data management plans was also a success. Poland conducted GATS entirely using a Web-based model while other countries were able to successfully manage data using memory cards and supervisor/regional aggregation and transmission.

After GATS was completed, a few countries (e.g., Bangladesh, China, Egypt, and India) have used the iPAQs and GSS software to conduct other surveys besides GATS, proving the sustainability of the methodology.

Lessons Learned

The success of using handheld computers to conduct GATS was not without shortcomings. Some of the main lessons learned:

Preparation Time/Capacity Building. While the basic structure of GATS was in place, many details of the standard protocol were still being finalized as the initial countries started implementing GATS. Thus, in certain instances there was limited time for some of the IT/data management preparations. While the time limitations did not affect overall data quality, they did have an effect on the ability to provide in-depth training for capacity building. Of the 14 initial GATS countries, the countries which conducted GATS later certainly benefited from the experience and lessons learned from the first countries to implement. For future GATS countries, time allotted for IT/data management preparations will be increased and the goal is to

provide more in-depth training during the pretest training workshop which hopefully reduces the training required at the main survey training workshop.

Enhancement of GATS GSS Questionnaire Program. There were no reports of major problems with the GATS GSS questionnaire program and corresponding case management system. However, there were many recommendations for enhancements of the program to help increase data quality. This included adding additional consistency checks, modifying range checks, and adding additional automated processes (e.g., auto coding field result codes). These enhancements have been incorporated for the next phase of GATS implementation.

Enhancement of GATS GSS PC Software. Countries also requested additional enhancements to the GATS GSS PC software suite, including enhanced reporting tools for improved monitoring of results and data quality during data collection, and an enhanced data aggregation program for ease of creating a master data set at the end of data collection.

CONCLUSION

Despite challenges in using electronic data collection methodologies in developing countries, the use of handheld computers was very successful for the initial implementation of GATS. The advantages of using CAI over paper and pencil to conduct surveys are well documented. However, there are potential obstacles for using CAI in developing countries including the potential insufficiency of resources, expertise, experience, and infrastructure. GATS proved that with resources and training, implementing surveys using handhelds could be successful in any country.

For GATS, the handheld computers provided advantages over other forms of CAI because of their portability and battery life compared to bulkier devices such as laptops. This was a distinct benefit for data collection in the GATS countries, particularly in rural and remote areas where electricity and transportation was often limited.

The use of handhelds improves the speed and quality of data collection and management for GATS. The significant gains in data accuracy, availability, and management, justify the implementation of handheld devices for GATS interviews and enhance the countries' capacity in using these devices for future non-GATS surveys.

Furthermore, the initial implementation of GATS has provided us ample evidence that the methodology of using handheld computers is sustainable for future GATS surveys and any other surveys. Adapting to emerging hardware (e.g., smart phones, portable tablets) and software (e.g., Android operation system) technologies will be key in sustainability.

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"I Don't Smoke but My Avatar Does!" Understanding the Unique Opportunities and Challenges When Collecting Health-Related Data in Virtual Environments

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INTRODUCTION

Though commonly called "virtual worlds", they are technically referred to as massively-multiplayer online role-playing games (MMORPGs). These worlds are framed by different narrative environments and are typically very sophisticated and elaborate worlds that evolve based on user interaction and imagination (Wood, Griffiths et al. 2004). Some more popular examples of this type of environment include World of Warcraft (WoW), Everquest, Neverwinter Nights, There, and Second Life (SL). Time spent in these types of environments is quite extensive with millions of users each spending an average of 22 hours a week interacting in these and many other virtual worlds (Yee, Bailenson et al., 2007).

Despite the seemingly unreal nature of these individuals and communities, the emotions and connections of virtual worlds residents are, in some cases, as genuine as those experienced in the physical world (Bell & Consalvo, 2009;Ikegami & Hut, 2008). As the largest virtual world of its kind, Second Life (SL) boasts millions of participants each month—called "residents"—and has an economy that is active and strong (LindenLabs, 2009). This has lead to significant interest in SL as a venue for health and education programs, commerce, and research. Many of the pioneers of health education and intervention in the physical world are experimenting with interventions in virtual worlds and early research seems to show support for financially investing in virtual world intervention programs as a viable tool for health behavior modification in the real world (Beard, Wilson et al., 2009; Krebs, Burkhalter et al., 2009; Norris, 2009).

Virtual worlds allow the researcher to change age, gender, ethnicity, or even the research environment with the touch of a button. Public health advocates have the potential to design interventions that elicit similar responses to those in a physical lab but they can quickly alter the scenario to match the needs of each individual participant for a much more tailored treatment program. Virtual worlds are a complex series of user-defined settings that, if harnessed properly, have great potential for research, education, and socialization.

BACKGROUND

MMORPG users typically interact with one another through the use of virtual representations of themselves, most commonly known as "avatars." The avatar is the self-representation of the individual and, in virtual worlds, is the primary identity cue for an individual (Yee & Bailenson, 2007) thereby being the most critical part of an individual's virtual identity. In some cases, the avatar may be human and closely resemble the individual in appearance, speech, and behavior; but in other cases the avatar may be completely nonhuman, such as a dwarf, elf, animal, or spirit. Although users typically gravitate towards familiar embodiment, they do frequently engage in "gender swapping" with their avatar. That is, a user who is gendered male in the physical world will present himself as a female avatar in the virtual world or vice versa. While reasons vary, it seems that in action-based virtual worlds, women tend to swap to male characters in order to avoid harassment or undue attention whereas male characters tend to gender swap in order to be treated better or to have easier social interactions (Hussain & Griffiths 2008). Because we, to

some degree, base our personal identity on what others see in us (Cooley, 1902), it is important to understand the nature of the interactions in virtual worlds and how they may or may not differ from that of the physical world.

HARNESSING VIRTUAL WORLDS FOR SOCIAL SCIENCE RESEARCH

Currently, the most widely discussed issue among virtual worlds researchers is how to conduct research in virtual environments with the same degree of scientific rigor that is used in physical world research. In order to do this, it is vital to understand the climate of education and research in virtual worlds and how individuals interact and behave in these environments.

Health-Related Research in Virtual Worlds

New technologies and their applications are growing and evolving as the "Net" generation—those who were born around the time that PCs were becoming popular and have always known this type of technology (Oblinger & Oblinger, 2005)—are entering adulthood. This connected generation does not draw boundaries between human and avatar, real and virtual, in-world and out-of-world in the same way that the generation before them did. The boundaries between countries may be geographically limiting in the physical world but through virtual worlds the individuals in these countries freely travel from world to world and island to island where they interact with other individuals across the globe.

Virtual worlds are increasingly being used for education, research and support—particularly in health-related fields. Currently, in-world research and demonstrations are being used to inform individuals about various health-related issues (Beard, Wilson, et al., 2009;CDC, 2009; WHC, 2009), to shape interventions (Bordnick, Grapp et al., 2004; Baumann & Sayette, 2006), to enhance health-related educational experiences (Walker, 2009), or to support or further challenge research conclusions from studies conducted out-of-world (Dean, Cook et al., 2009).

Represented in SL are many of the major names in health care and wellness in the United States. Virtual facilities exist where residents can get health-related information (CDC, 2009), participate in focus groups (CDC, 2009; Dean, Cook et al., 2009), or simulate a virtual breast mammogram (Beard, Wilson et al., 2009). In the realm of mental health support, the SL site called Virtual Hallucinations simulates the perceptual abnormalities that schizophrenics often experience helping to educate users on the strain of daily living for those with mental illness (Beard, Wilson et al., 2009; Schizophrenia.com, 2009). The hope is that these innovative sites will help to bring often-uncomfortable topics to an area where people can interact and educate themselves with relative anonymity.

Changing Health Attitudes & Behaviors among Humans via Their Avatars

Researchers at RTI International found that individuals whose avatars engaged in health behaviors in-world were more likely themselves to engage in physical activities in the real world than were those individuals with avatars who were less physically active (Dean, Cook et al., 2009). Further supporting this was a recent experiment conducted by Fox and Balienson (2009) that showed that people who watched "self-representing avatars" (i.e., avatars whose physical characteristics are designed to look like the human they represent) exercise on a treadmill were more likely to engage in some form of physical exercise in the 24 hours following the virtual exercise—indicating the real possibility of modifying behavior in the real world through virtual world interaction. What is unclear from this research, and is an area of debate in the literature, is whether the fit individual creates a fit avatar or if the creation of a fit avatar motivates the

individual to act in a way that he/she believes is expected of him/her—a phenomenon called the "Proteus Effect." The extent to which this operates in virtual worlds and the impact of this effect has large implications for research in terms of understanding how the individual and avatar work together or separately and raises many questions. For instance, if an avatar engages in a virtual world based research project, what impact, if any, does that have on the real person? Can researchers modify the health behaviors of individuals by engaging their avatars in health behaviors?

Recent and emerging research that targets and engages a wider range of virtual worlds, such as Second Life, is finding that while the user dictates the activities of the avatar there may be a reciprocal effect—meaning that while the human drives the activities of the avatar, the avatar also drives the actions of the human (Yee & Bailenson, 2007; Dean, Cook et al., 2009). The underlying theory for this is that humans are likely to create avatars that are generally better representations of themselves (physically at least) (Dean, Cook et al., 2009) and the expectations of those thinner, fitter, and healthier avatars begin to change the behavior of the individual (Walther, 1996; Yee & Bailenson, 2007). In a sense, they begin to act the part of a healthier or more attractive individual.

Finally, in a similarly set up experiment Yee and Bailenson (2007) manipulated the participant avatar's height and found that participants with taller avatars were more likely to behave in a confident manner and negotiate for things more aggressively than were shorter avatars. Based on these findings, the researchers concluded "the appearance of our avatars shape how we interact with others. As we choose our self-representations in virtual environments, our self-representations shape our behaviors in turn. These changes happen not over hours or weeks but within minutes" (Yee & Bailenson 2007, p. 287). Even simple clothing changes, such as the color of the avatar's robe, can impact the desired behaviors of the user (Merola, Penas et al., 2006). Graphical avatars are the dominant way to represent one's self in virtual worlds (Walther, 1996) and as this form of representation increases so too will the interplay between the human and the avatar (Yee & Bailenson, 2007). The fact that a person's avatar changes their behavior, coupled with the speed at which the change occurs, is especially encouraging for interventions aimed at changing health related attitudes and behaviors.

HEALTH-RELATED DATA COLLECTION IN VIRTUAL ENVIRONMENTS

Opportunities

Chief among the many benefits of collecting data in virtual environments is how "real" the virtual world actually is to its residents (Blascovich, 2002) and how closely the behaviors in virtual environments mimic those in physical environments (Yee, Bailenson, et al.,2007). Underlying the seemingly surrealistic virtual environment is a true community that, in many ways, operates similarly to the physical world in its social norms and behaviors (Yee, Bailenson et al., 2007; Ikegami & Hut, 2008). While the landscape and the avatars that an individual interacts with may be virtual, the person behind the avatar is real, and the emotions that he or she feels can be as real as those experienced in physical worlds (Ikegami & Hut 2008). The real presence that an individual feels in a virtual environment allows that person to behave and interact in a way that is familiar to social scientists thereby making it possible to create education and intervention programs and to collect health related data.

Manipulating the research environment. In interacting in this environment, researchers have learned that one of the biggest opportunities is the ability to manipulate virtually all aspects of the research environment. This is important because research indicates that the physical attributes of the research avatar can impact the responses from a participant. In a study manipulating interviewer characteristics, Dean et al.

found that avatars were more likely to report having a heavier SL body size and higher real life BMI to a heavier avatar than they were to a thinner avatar (2009). With very little work, a researcher can change his or her appearance in any number of different ways. Along the same lines, since an individual can manipulate their virtual presence it provides a level of perceived anonymity in interactions that may possibly result in more honest answers when responding to sensitive health questions (Foster, forthcoming).

Reduced cost. Another large opportunity in virtual environments is the relative cost of conducting research. Conducting research in virtual environments is generally less expensive than in physical environments because there are no brick and mortar buildings to build and maintain, no transportation costs to account for, and the speed of collecting data is often quicker (thus lessening the general cost). In addition to the cost savings of not having physical sites, there is a significant difference in the cost of incentives in virtual worlds. In Second Life, the typical incentive for participation in a survey is $250 Linden Dollars—about $1 U.S. dollar. This incentive amount has been proven to be highly effective at recruiting participants for survey participation (Bell, Castronova et al., 2009; Dean et al., 2009; Foster, forthcoming) and is significantly less than what most recruitment incentives used in the physical world.

Challenges

Interestingly enough, even though virtual worlds offer unparalleled advancements in technology, teaching, and entertainment, they are not always terribly easy to work with for those wishing to conduct serious research on virtual world residents. Well-established educational and research institutes currently are examining the necessary tools needed to engage virtual worlds residents in research that adds to the body of knowledge particularly around methodological issues such as sampling (Bell, Castronova et al., 2008; Bell Castronova et al, 2009) and interviewer effects (Dean, Cook et al., 2009). Wood, Griffiths, and Eatough (2004) identified four key areas of methodological concern when conducting research in virtual worlds—recruiting and utilizing research participants, viable methods of data collection, validity of data collected, and ethical issues.

Sampling and Data Collection. One of the biggest issues facing researchers in general, and virtual worlds in particular, is how to get individuals to participate in research projects and how to select them in a manner that does not introduce any undue bias into the project—usually accomplished through sampling (Wood, Griffiths et al., 2004). There are two broad categories in which most samples fall—those selected at random and samples of convenience. The problem with samples of convenience is that there is usually no known probability for each respondent, which means that any generalizations must be based on nonstatistical grounds (Keppel & Wickens, 2004). This is in contrast to a random sample, in which respondents are drawn from a known population such that each member has an known probability of selection; and, if done randomly and appropriately, will ideally yield results very close to what would have been achieved by interviewing each member of the population.

However, random sampling in virtual worlds is difficult because very few, if any, worlds share information about their users. There is no phone book so they cannot be called, no permanent addresses to send a letter, and no easy way to randomly identify individuals. Unfortunately, this makes it all but impossible to design a random sample where each individual has an equal probability of selection. At present, most research in virtual worlds relies on convenience samples, which can be problematic when trying to generalize to a broader population (Keppel & Wickens, 2004).

At the present time are only two surveys completed in Second Life that can make a reasonable claim to have randomly collected data (Bell, Castronova et al., 2009; Foster, forthcoming) and to examine those data

with ones collected via convenience methods. There were no differences between the random and convenience sample groups in the Foster study and the only real difference between the quasi-random sample and the other samples in the Bell, Castronova et al. study was age and income—both of which showed a more spread out distribution in the quasi-random protocol than they did in convenience protocol. After reviewing the participation rates and analyzing data as well as comparing the relative cost of each method both studies concluded that the differences between the random protocol and the convenience protocol modes are not large enough to warrant the increased expense (Bell, Castronova et al., 2009; Foster, forthcoming).

Data Validity. When collecting data from a resident of a virtual world, many of the visual and aural cues that both researchers and participants rely on in the physical world are absent. For instance, a virtual researcher can ask the gender of a resident but they have no way to verify the actual gender of the individual behind the avatar whereas in the physical world they would be able to determine this with a reasonable degree of certainty from seeing the participant or talking with them. Although the problem of verification is highlighted in virtual world research, it is largely similar to any self-reported data that is administered remotely (such as a questionnaire by mail or telephone) and requires the researcher to build in checks (such as follow-up communications) to attempt to determine the validity of the data (Wood, Griffiths et al., 2004).

Larger threats to data validity, and ones that are rarely addressed by researchers in their writings, are technical and interference issues (such as hacking, harassing, and generally disrupting the process – also broadly referred to as "griefing" in virtual worlds) that can immobilize the entire research project and destroy or corrupt all the data collected. In the best of situations it is nearly impossible to conduct a research project without some level of technical difficulties, whether that is making sure that your survey participants understand the questions on paper, trying to minimize interviewer effects in telephone surveys, or ensuring that all proctors administer exams with the same instructions. However, surveying in virtual worlds brings a whole new host of technical issues that require specialized learning to address such as server protection and security, programming, and general technical literacy. Another big issue is that the environment in which the research is conducted is largely out of the researcher's control (Bell, Castronova, et al., 2009) such that if the host world experiences a glitch and is forced to shut down then so is the research project.

In most virtual worlds there is a "general absence of law and some degree of social indifference" (Bell, Castronova et al., 2009 P.6) that proves to be a breeding ground for organized crime groups and other lone individuals who seek to disrupt the experiences of other residents (called "griefers"). In general, griefers are individuals who are very skilled at virtual world play and online games but "what they most enjoy about these games is making other players not enjoy them" (Dibbell, 2008, p. 2). Griefers have recently become an issue to the research field as they attempt to hack into payment systems or fill out surveys in a manner that indicates that the information was not true (Bell, Castronova et al., 2009; Foster, forthcoming). This oftentimes forces the temporary suspension of research projects and can yield unusable data. These individuals and groups can make conducting research unpredictable and put data collection and quality at risk, but unfortunately there is not a great deal that a researcher can do to prevent these occurrences. Generally they just have to be dealt with when or if they happen by taking steps to ensure that research accounts are monitored and data is properly vetted and cleaned (Bell, Castronova et al., 2009).

Ethics. The ethical issues in virtual worlds research are not terribly different from that of the physical world. Mckee and Porter (2009) suggest that most of the ethical issues under consideration for virtual worlds—informed consent, respondent burden and stress, vulnerable populations—all have some

counterparts in the physical world. For instance, researchers know they must gain informed consent from a person before beginning a research experiment. But, an avatar is not a human. Should it be afforded the same protections as a human? What about private space? Is there such a thing as "private space" in a totally open society such as Second Life? In 2004, researcher Malin Sveningsson argued that the public-private dichotomy is not sufficient to determine ethical judgments (Sveningsson, 2004) particularly in a virtual world. Instead, she stated, one must consider both the issue of the public vs. private sphere as well as how sensitive the information is to the respondent (Sveningsson, 2004).

Compared with traditional research participants, those in virtual environments may be at increased risk for respondent stress due to the lack of verifiable non-verbal cues (such as age, race, gender, inflection in voice, and eye contact) (Woods, Griffiths et al., 2004). Additionally, researchers are able to modify their appearance to mask their real age, ethnicity, or gender thereby conveying an identity that is not truly theirs which can also increase respondent stress. In the absence of these indicators that convey unspoken meaning, researchers should take great care to create environments and word questions in such a way as to ensure clarity and meaning, avoid deception, and respect a participant's right to privacy (Wood, Griffiths et al., 2004). Along these same lines, they suggest that since there is no way to determine with certainty who is behind the avatar participating in the study, it is important to consider the presence of typically vulnerable populations (Wood, Griffiths et al., 2004) and to act accordingly.

DISCUSSION

The opportunities for collecting health related data are many as are the challenges. While it is certainly difficult to design research projects that utilize conventional methods with regards to sampling and data collection, the rewards for being able to "think outside the box" and develop new methods is vast. Researchers are able to modify their gender, race, age, and environment in ways that could potentially increase respondent comfort and reduce the desire to provide socially acceptable responses. By giving respondents another layer of anonymity and protection, it is possible to obtain more truthful responses which could lead to more effective health related education and interventions. Additionally, since the avatar and the individual are one in the same, there is great potential for impacting the health of the real individual through interventions that target the behavior of the avatar. Research in virtual worlds is a rapidly evolving science that, while similar to research in the physical world, does have very different methodological and ethical challenges that must be approached with the same degree of seriousness as research in the physical world.

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HINTS-GEM: Using Science 2.0 to Construct a National Health Survey through Community Engagement

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INTRODUCTION

With the rapid increase in the use of the Internet and its capabilities, scientists are taking advantage of collaborative Web technology to accelerate discovery in a new participative environment, a phenomenon referred to as Science 2.0 (Shneiderman, 2008). This builds off the idea of Web 2.0—defined by technologies such as wikis, blogs, and other means for sharing information and collaborating with other users (e.g., seeing comments and ratings by users of Amazon.com) with specific application to the scientific arena. These technologies can be seen as a way of creating a new collaborative environment of openness, transparency, and crowd-sourcing (i.e., wisdom of crowds; Surowiescki, 2004). Likewise, there is a recent push within the Federal government toward openness and transparency, exemplified by the Open Government Initiative (www.whitehouse.gov/open/), which seeks to "…establish a system of transparency, public participation, and collaboration." This movement extends to the Federal data system through sites like Data.gov and Healthdata.gov, which provide—free to the public—a large number of data sets and data tools for public consumption. This movement toward openness and transparency, in part, aims to increase knowledge and engage and empower communities (broadly defined) to improve their health. The Community Health Data Initiative (CHDI; www.hhs.gov/open/datasets/communityhealthdata.html) is a Department of Health and Human Services (DHHS) program under the Open Government Initiative that seeks to empower consumers and communities to get more value out of the myriad sets of health data that exist in the U.S. This initiative provides data and tools in user-friendly formats to increase disease prevention, health promotion, and health care quality and performance. Now more than ever, the public has access to quality data to inform their health decisions and empower their communities around wellness.

In addition to efforts to promote and enable use of existing data through initiatives like the CHDI, communities increasingly are encouraged to collect their own data and use existing measures to ensure that their results can be compared with existing data. In keeping with this idea, a 2010 Institute of Medicine (IOM) report on the role of measurement in the Federal surveillance system states that communities need data and indicators of health to make important decisions; however, it cautions against creating a plethora of indicators that could create more confusion than clarity. One of the seven recommendations to come from this report states that DHHS should create (a) a core standardized set of indicators that can be used to assess the health of communities and (b) a core standardized set of health-outcome indicators for national, state, and local use. One effort to address the need for standardized indicators is the recently created Health Indicators Warehouse (www.healthindicators.gov/), which provides a large number of indicators organized by topic, geography, or initiative, with the goal of providing outcomes that can be harmonized and directly compared across different levels. Thus, it is important to not only make data publicly available to empower communities but also encourage the use of shared indicators of health outcomes to maximize the utility of data collection efforts.

HINTS & HINTS-GEM

Open data, data harmonization, and empowering communities are basic tenets underlying the National Cancer Institute's (NCI) Health Information National Trends Survey (HINTS). In this report, we describe a Web-based tool called HINTS-GEM, which was created to leverage the collective intelligence of a large group of researchers committed to using national surveillance as a means to improve cancer prevention and control. HINTS-GEM is an extension of another of NCI's tools—the Grid-Enabled Measures (GEM) database—that contains behavioral and social science measures organized by theoretical constructs and is designed to enable researchers to use common measures with the goal of exchanging harmonized data. (Further detail on GEM is provided below.) Engaging a variety of researchers in the process of building a HINTS instrument is not new; collaboration has been central to the HINTS program since its inception, and the data collected by HINTS have always been publicly available (further details on the HINTS program are provided below). However, for the current iteration of HINTS (HINTS 4), the NCI made a commitment to build upon the Open Government Initiative and activities like the Community Data Health Initiative to capitalize upon technology-mediated social participation to enable a transparent process for the development of content for HINTS 4, with the goals of increasing the breadth and depth of input from a community of researchers and health advocates.

THE HEALTH INFORMATION NATIONAL TRENDS SURVEY (HINTS) PROGRAM

HINTS is a national health communication survey conducted by the NCI, which has the vital mission of developing and implementing programs that prevent and reduce the incidence of cancer. HINTS was designed to support the mission of the NCI's Health Communication and Informatics Research Branch (HCIRB) by providing a means to systematically evaluate the public's knowledge, attitudes, and behaviors relevant to health communication and cancer prevention and control, which have not adequately been studied through other national data collection efforts prior to HINTS.

PURPOSE OF HINTS

The HINTS framework takes into account that the successful development and communication of public messages about cancer prevention, detection, diagnosis, treatment, and survivorship require comprehensive understanding of individuals' access to cancer-related information, perceived trust in information sources, cancer- and health-related knowledge, and in-depth knowledge of the factors that facilitate or hinder communication. HINTS aims to assess the public's use of health information in an environment of rapidly changing communication and informatics options and allows the intramural and extramural research community access to the data to conduct research into the relationships between health information, knowledge, attitudes, and behaviors. Prominent constructs and resultant item development for HINTS were informed by the emerging theories of health communication (Glanz, Lewis, & Rimer, 1997), media usage (Viswanath & Finnegan, 1996), risk information processing (Croyle & Lerman, 1999; Fischhoff, Bostrom, & Quadrel, 1993), diffusion of innovations (Rogers, 1995), and behavior change (Weinstein, 1993). A more detailed discussion of the conceptual framework underlying item selection is published elsewhere (Nelson et al., 2004).

HINTS-GEM

For the first three HINTS data collection efforts, instrument development relied upon a collaborative process involving relevant content including intramural staff at NCI and colleagues external to the government, in academic and research settings. HINTS 4 will include four data collection cycles over the course of three years, beginning in October 2011. The instrument for each data collection cycle will include a core module of trended items in addition to special topic modules to be implemented in only some of the cycles, increasing capacity of the HINTS instruments to include additional topics and measures.

RATIONALE & GOALS

The guiding framework for HINTS highlights the multiple factors that play a role in understanding the role of health communication in cancer prevention and control. Given the variety of perspectives that must be taken into account for successful instrument development, the HINTS program has always solicited input for the HINTS instruments from a community of researchers. These researchers represent a number of disciplines including behavioral science, clinical psychology, social psychology, communication science, and health behavior. For HINTS 4, the NCI asked researchers who wanted to "help build a better HINTS" to use HINTS-GEM as a forum for their input.

The NCI had four goals in building HINTS-GEM:

- Increase the efficiency, organization, transparency, and success of building an item pool for the HINTS 4 instruments;
- Broaden participation in the instrument building process, both with respect to the number of participants and the substantive content represented by participants' areas of expertise;
- Enhance the degree to which researchers are engaged with the HINTS Program—e.g., using HINTS data or HINTS instruments in their own research—by increasing their opportunities to be a part of the HINTS 4 process from the very start; and
- Keep a community of researchers engaged and up-to-date with the HINTS 4 modular data collection process over its three-year administration period.

DESIGN

HINTS-GEM copied the basic design and infrastructure of the NCI's Grid-Enabled Measures Database (GEM; www.gem-beta.org). Briefly, GEM is a grid-enabled, interoperable Web site of behavioral and social science measures. In GEM, researchers have the opportunity to search, download, and provide feedback on measures as well as share data that result from use of the measures. In GEM, content is primarily divided into *constructs* and *measures*, where constructs represent larger areas of inquiry (e.g., cancer information seeking) and measures are scales or single items that assess a specific outcome (e.g., "During your last search for cancer information, how concerned were you about the quality of the information?"). Each measure is assigned to one construct, though each construct may contain several measures (a "one-to-many" relationship; see Figure 1).

HINTS-GEM development began in June 2010. At that time, 81 constructs appeared in GEM; these were imported into HINTS-GEM so that the site was initially populated with these 81 constructs. Next, HINTS-GEM was populated with measures, including every item that appeared on a previous iteration of HINTS (the 2003, 2005, and 2008 instruments). These 526 items were assigned constructs by the HINTS Management Team. As needed, new constructs were created.

Figure 1. HINTS-GEM Measures Page

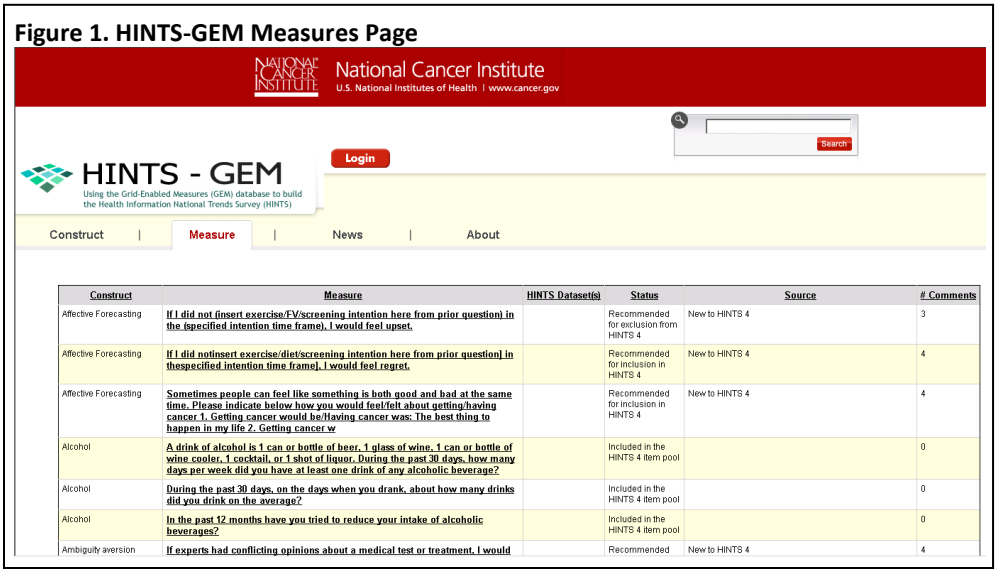
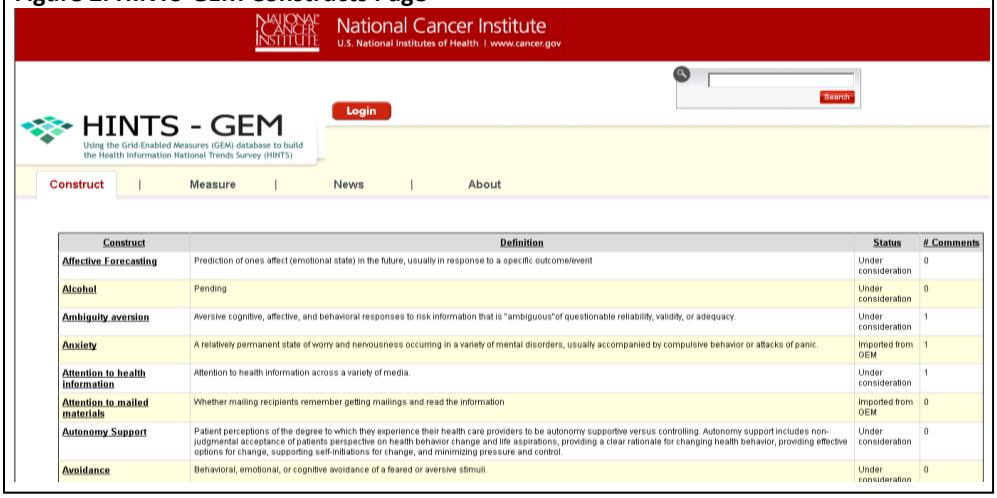


Figure 2. HINTS-GEM Constructs Page



The HINTS-GEM site includes four separate tabs: one for constructs, one for measures, one for news, and one labeled "About." The news tab is used to push announcements out to the HINTS-GEM user community. (News tab posts usually are accompanied by an e-mail blast to registered users, directing them to HINTS-GEM for more information about the announcement.) The "About" tab includes links to a Web-based orientation to HINTS-GEM and a HINTS-GEM fact sheet.

The main functional capabilities of HINTS-GEM are contained within the Construct and Measures tabs. The Constructs tab shows a data spreadsheet with four columns: construct name, its definition, its status, and the number of comments attached to the construct. A construct's status could have one of two values: Imported from GEM (if the construct was prepopulated into HINTS-GEM via GEM) or Under Consideration (if the construct was created by a HINTS-GEM user). (See Figure 2.)

The Measures (i.e., Items) tab shows a data spreadsheet with six columns: The construct associated with the measure; the measure text; the HINTS data set(s) in which the measure previously appeared (a missing value for this column indicates the measure was newly proposed for HINTS); the measure's status; its source; and the number of comments attached to the measure. A measure's status could have one of three

values: Recommended for Inclusion in HINTS 4; Recommended for Exclusion from HINTS 4; or Under Consideration. (See Figure 1.)

Functional capabilities. Five functional capabilities exist within HINTS-GEM:

- Users can *contribute* content to the data set by adding new constructs or measures (i.e., items) for consideration by the user community. Meta-data (information that describes the construct or measure—e.g., definition, source) are required for both. When adding a new construct, users are required to supply a definition but are encouraged to enter other information such as theoretical foundation and synonymous constructs. When adding a new measure, users are required to assign the measure a construct (and are given the option to create a new construct, if the one they are looking for does not exist, as part of the process); to specify the measure's response option(s); and to indicate whether the measure is a trend measure (i.e., has appeared on a previous iteration of HINTS); appears on another survey (and if so, which survey); is central to a theory of health behavior (and if so, which theory); or appears in the Cancer Data Standards Registry and Repository (caDSR).[3] Finally, users are asked to provide a brief comment that explains their rationale for adding the measure to HINTS-GEM.
- Users can *comment* on constructs or measures using free text.
- Users can *rate* measures on a scale from one to five with five being the highest rating.
- Users can *propose alternatives* to measures in lieu of creating a new measure, if what they want to propose is substantively similar or related to a measure that already appears in HINTS-GEM.
- Users can *sort* the interface by any column header and can *search* HINTS-GEM for specific content.

The meta-data requirements for adding new measures to HINTS-GEM were intended to encourage users to consider factors related to measure standardization and data harmonization. While users were free to add any measure they chose to HINTS-GEM, by requiring meta-data on a measure's trend potential, its appearance in another surveillance effort, its relationship to theory, and its status in the caDSR, the HINTS Program aimed to encourage HINTS-GEM users to propose new content for HINTS 4 commensurate with one (or more) of these features. The hypothesis was that doing so would solicit new content from HINTS-GEM users that met these requirements and would therefore lead to the HINTS 4 data having good potential for harmonization with other surveillance efforts at multiple levels (e.g., local, regional, national, and global).

BUILDING A HINTS-GEM COMMUNITY

Concurrent with the development of HINTS-GEM, the NCI began work on building a community of researchers to use the site. This work happened in two phases:

Enlisting Participation from HINTS Champions. Twenty-one HINTS Champions (i.e., individuals who had contributed to HINTS development in the past or who were known by NCI to be HINTS data users) from the extramural research community and internal to NCI were initially invited to be the first HINTS-GEM users in August 2010. These Champions participated in an online HINTS-GEM orientation in September 2010. Champions were assigned content areas (i.e., constructs) based on their areas of substantive expertise and/or content they had helped to develop in previous HINTS instruments. Champions were charged with three tasks to complete by the end of October 2010. First, they were asked to review the

[3] The caDSR is a tool associated with the cancer biomedical informatics grid (caBIG); it creates and deploys common data elements to be used by the cancer research community. For more information, see https:/cabig.nci.nih.gov/concepts/caDSR/

measures already contained within HINTS-GEM (i.e., measures that had appeared in a previous iteration of the survey) and assign the appropriate status to each. If a Champion wanted the measure to be considered for HINTS 4, then they indicated a status of "Recommended for Inclusion in HINTS 4." If they thought the measure should be excluded from HINTS 4, they changed the status to "Recommended for Exclusion from HINTS 4." Finally, if they wanted a larger community to have input into the decision, they left the measure's status as "Under Consideration." Second, Champions were asked to populate HINTS-GEM with new measures for consideration in HINTS 4. Finally, Champions helped to disseminate information about HINTS-GEM to a broader community of research using prepared e-mail blasts and PowerPoint slides for use at conferences or in communication with their respective professional societies.

Enlisting Participation from General Users. Concurrently, NCI prepared a larger HINTS-GEM promotion campaign for launch at the 2010 American Public Health Association (APHA) annual meeting held in early November 2010 in Denver. HINTS Program staff was available on-site during the meeting to demonstrate HINTS-GEM and to register new users to the site. HINTS-GEM Fact Sheets were available at the meeting, information about HINTS-GEM was disseminated via the HINTS Web site (http://hints.cancer.gov), and an e-mail describing HINTS-GEM (and directing potential users to an online HINTS-GEM orientation) was sent to all e-mail addresses on record with the HINTS Program. These e-mail addresses represent individuals who had asked to download HINTS data in the past or who had reached out to the HINTS Program for another reason. General HINTS-GEM users had all the same functional capabilities as HINTS Champions except that general users were unable to change the status of measures.

Periodic e-mail announcements and HINTS-GEM news items were sent and posted to encourage continued participation in HINTS-GEM after the official launch to a broad community of researchers at APHA. The HINTS Program provided technical support to HINTS-GEM users as needed. Communication with the HINTS-GEM community first emphasized adding measures to HINTS-GEM (November 2010–December 2010), moved to commenting on measures (January 2011), and finally focused on rating measures in HINTS-GEM (February 2011–March 2011). In March, 2011, all measures in HINTS-GEM with a status of "Recommended for Inclusion in HINTS 4" or "Under Consideration" were submitted—as required by all public surveys—to the Office of Management and Budget (OMB) as an "over-inclusive item pool." This pool represents the group of items that researchers will select from as they work with the HINTS Program to build the HINTS 4 instruments. Final disposition by HINTS status can be seen in the table below.

Measure Disposition, by HINTS Status

Measure Disposition	Measures from Previous HINTS Iterations (*n* = 526)	Measures Newly Proposed for HINTS 4 (*n* = 647)
Recommended for inclusion	37.6%	41.7%
Recommended for exclusion	36.5%	6.3%
Under consideration	25.9%	51.9%

RESULTS

There were 51 HINTS-GEM Champions and an additional 87 users who contributed to HINTS-GEM. Most users came from academia (52%) or government (30%), though the private sector (10%), advocacy groups (4%), and HMO/medical centers (4%) also were represented. Although users were required to register in order to participate (for tracking and accountability purposes), they only were asked for their name and affiliation, so detailed information about them is limited.

HINTS-GEM was initially seeded with 81 constructs from GEM and 526 measures from all three previous iterations of HINTS. By the end of the campaign, four new constructs and 647 new measures had been proposed, resulting in a total of 85 constructs and 1,173 measures in the HINTS-GEM database. The total number of measures (both existing and new) were spread across the constructs with several having a large number of measures (tobacco use = 130; colorectal cancer = 75, use of technology = 69, health information seeking = 60) and others having very few measures (for example, belief in a just world = 1, religiosity and spirituality = 1). A total of 60 alternative measures were proposed as potential replacements or alterations for existing measures.

Across all measures, the number of comments ranged from 0–8 with 167 (14%) having no comments and a majority (71%) having one or two comments. Regarding ratings, a large majority had no ratings (89%), and for those that were rated, most had only one related comment (9%). The ratings themselves tended to be negatively skewed such that 87% of measures with ratings had an average value of 4 or greater (range 1–5, with 5 being the "best" measure). In regards to the reasons for including a new measure, out of the 647 new measures proposed, the following results were seen: (1) This is a trends measure (4%), (2) This measure appears on another survey (19%), (3) This measure is central to a theory of health behavior (9%), and (4) This measure is designated in the Cancer Data Standards Registry and Repository (0%).

THE FUTURE OF SURVEY DESIGN: OPENNESS, DATA HARMONIZATION, & EMPOWERING COMMUNITIES

Now more than ever, researchers and survey methodologists have access to vast amounts of information and data—it truly is the era of Big Data (Nature, 2008). However, a lack of resources to manage this data deluge—including computer processing power, which is sorely lagging behind (King, 2011)—are hampering our ability to move science forward quickly and efficiently. We need better tools so we can take advantage of these data.

There is also a sense that in the Federal government surveillance system, we can do more with what we have. Conducting more surveys does not seem to be the answer; conducting better surveys in a systematic and coordinated fashion does. This means creating agreed-upon health indicators and outcomes that can be shared and used by others. If this can be accomplished more readily, the ability to compare across data collection systems will be enhanced (IOM, 2010). It also means systematic planning across data collection systems to avoid duplication of efforts or just as importantly, to identify gaps that need to be filled. This can decrease costs, increase efficiency, and allow researchers to learn and build off each others' work—that is, build a cumulative science. Evidence of tools to enhance collaboration and harmonize data already are available but primarily are focused on enhancing smaller-scale research protocols, rather than on capitalizing upon population-level surveillance systems. These tools, such as PhenX (consensus measures for Phenotypes and eXposures; https://www.phenx.org/), GEM (Grid-Enabled Measures; www.gem-beta.org), the NIH Toolbox (www.nihtoolbox.org/default.aspx), and PROMIS (Patient Reported Outcome Measurement Information System; www.nihpromis.org/), have similar goals of pushing for the use of common measures that can be used by the research community. The overall idea is that if researchers can agree *a priori* on which measures to use in their research, the ability to share resulting harmonized data and build a cumulative science increases.

HINTS-GEM was built to increase the HINTS Program's commitment to and enablement of measure sharing and data harmonization. The results presented here suggest that the NCI achieved success at several levels through use of HINTS-GEM. Not only did the number of researchers who engaged in the HINTS

development process greatly increase over years past, but the amount of new content proposed, as well as consensus regarding existing HINTS content, increased as well. Additionally, the more than 100 HINTS-GEM users who engaged in the process of building the HINTS four-item pool are now in a position to use the consensus-driven measures found in HINTS-GEM in their own research, thus allowing for harmonization between local and national surveillance efforts.

The HINTS Program already has engaged in this sort of partnership: in 2009, the NCI partnered with the University of Puerto Rico to field a HINTS survey in the U.S. territory of Puerto Rico. Because there was a conscious effort to reuse the same items from HINTS 2008, there now exists ways of making direct comparisons in outcomes between the two surveys and associated geographic areas. The development of similar partnerships is currently underway, and these future efforts will be able to make use of the HINTS-GEM infrastructure to increase the efficiency and effectiveness of these endeavors.

There are several next steps for using HINTS-GEM. The site will be used to solicit further input to build consensus around the items that are selected for the Cycle 1, 2, 3, and 4 HINTS 4 instruments. HINTS-GEM also will be used to communicate with the HINTS community about final item selections so researchers can field local HINTS data collections in concert with the national-level data collection if they so choose. Finally, when HINTS 4 data are collected, the data will be made publicly available on HINTS-GEM, with the opportunity for researchers to share their own local HINTS data collections via the site.

CONCLUSION

Technology is now enabling access to vast amounts of data; it also provides new ways of collaborating and conducting science. This new paradigm, referred to as Science 2.0, has the capability of moving science forward in ways we are just starting to understand. This paradigm was utilized by the HINTS Program as it took collaborative science regarding survey content to a new level. The data from the HINTS-GEM experiment suggest that the results of this elevation in changing the process of collaboration will lead to better surveillance instruments, more actively engaged researchers, harmonized data across surveillance efforts, and greater power to detect meaningful results that can be translated into policy and practice aimed at improving health and wellness.

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SESSION 5 DISCUSSION: Why Aren't Survey Researchers Better at Leveraging New Technologies?

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Advances in survey methodology over the past 30 years largely have been the result of or were facilitated by the adoption of new data collection technologies. Innovations in computer-assisted interviewing, personal computers, and software development to facilitate automated data editing and sophisticated analyses, and new platforms such as the Internet that now allow respondents to participate at the time of their choosing have all contributed to the advancement and refinement of what we might call "classic" or "traditional" survey research (i.e., the administration of a questionnaire for the purpose of obtaining information from a respondent). Over the past decade, the growth and development of innovative technologies that can be used to collect information from publics of interest has grown exponentially. Smartphones with their associated applications and audio/video/GPS capabilities, social networking, techniques for obtaining data from Web pages, and virtual reality environments are just some of the new potential tools at the disposal of survey researchers. In fact, the potential has never been greater to make real and significant advances in data collection methods, offering researchers, policy makers, the public, and other data consumers new insights into health-related behaviors and attitudes. As the papers presented in this section attest, there are a wide array of potential new frontiers to explore (see Baker, 2011; Foster, 2011; Morton, Palipudi, & Asma, 2011; Moser, Beckjord, Rutten, Blake, & Hesse, 2011; Murphy, Dean, Hill, & Richards, 2011).

Yet, while the potential is great, the level of research among traditional survey researchers in these areas is quite anemic. What is missing is the research and development engine that was so powerful in moving the field forward in the 1970s and 1980s. While there are some obvious reasons for the dearth of research with these new technologies, such as the severe tightening (or complete lack, in some instances) of resources and funding as well as the closing of many university-based survey laboratories, there are likely other factors at work as well. Given the potential transformative impact ready adoption of new techniques and approaches could have on our industry, it's important that we ask ourselves a basic question: Why aren't survey researchers in this day and age better at leveraging new technologies?

TECHNOLOGY: THE PROMISE & THE RUB

Survey researchers often talk about new technologies as having four key advantages. First, technology can help to increase the *speed* of data collection. This is certainly true when we consider the move from paper-based questionnaires to computer-assisted questionnaires. With the former, the tasks of data entry and data cleaning/editing/quality control can considerably reduce the time it takes between data collection and data analysis. With computer-assisted approaches, the recording of data into an analyzable data set is nearly instantaneous. Second, computerized systems facilitate greater *data accuracy* via built-in checks—such as valid data range checks and response verifications—that can be shown on a screen so that incorrect responses can be quickly addressed. There are also numerous "back-end" data quality checks that can be automated, thereby increasing the quality of the final data output. Third, technology facilitates the

[4] The thoughts and views expressed here are solely those of the author and do not necessarily represent the official views of The Nielsen Company.

administration of more *complex questionnaires*, with more complicated skip patterns and dependency questions, and longer overall questionnaires with multiple paths. As a result, researcher typically can collect more data with computerized systems than is usually possible with manual methods. Finally, use of technology is often discussed in terms of greater *cost-efficiencies*. This may or may not be the case depending on many factors, not the least of which are design, capital costs, and the level of resources required.

What is instructive, however, are the types of advantages offered by technology that survey researchers typically do *not* discuss. These include the potential for *direct measurement* of behaviors (and potentially attitudes inferred from behaviors) rather than reliance on self-reports. Such approaches, if executed properly, could provide a significant boost to data accuracy, reducing the biases and measurement error inherent in a typical recall survey design. Second, technology can facilitate *in-the-moment measurement* of behaviors and attitudes—that is, provide measures that coincide with a behavior rather than depending on respondent recall to capture the activity. The standard survey design is very dependent upon respondent recall. For example, consider questions such as "In the past 30 days, how many times have you had one or more drinks of alcohol?", "In the past year, how many times have you visited a doctor?", "In the past week, how often did you dine at a fast food restaurant?" These are data elements that could be captured as they occur—either through a device used by the respondent to record the event or a passive system based on GPS coordinates. Finally, there is seldom talk among survey researchers about how new technologies might provide new types of data and fresh insights—data that could augment or even replace traditional survey data. For example, the use of Web "spidering" techniques to determine Internet "buzz" (i.e., the recurrence in postings and blogs of particular key words, concepts, or phrases) on a particular topic could serve as an indicator of public sentiment on a particular topic. Smartphones, pad-technology (such as the iPad or Galaxy), collection of visual data, GPS information, and customized metering technologies are all critical technologies in other industries but not widely researched or used within more traditional survey research circles. The low visibility and discussion of these types of benefits of technology raise concerns about how survey researchers view and therefore use new technologies more generally.

A critical question we need to ask ourselves (e.g., the traditional survey research industry) is "What's impeding us from making more rapid progress in the development and use of new technologies?" As strange as this might seem, perhaps the paradigm that facilitated a golden age in survey research is actually the framework that holds us back. In other words, is our thinking about new technologies constrained by or trapped within a well-established "Survey Paradigm," one that defines (a) how we think about the world, (b) how we measure phenomena of interest, (c) how we go about designing our work and (d) how we think about ourselves in terms of our professional identities? This is not to say that the "Survey Paradigm" is "bad" or "flawed" *per se*, but rather that when it comes to viewing (and perhaps even imagining) uses for new technologies, the overarching dominant paradigm tends to constrain our thoughts and limit our ability to maximize the full potential of many technologies.

How might we accelerate this process? It requires that we think differently about technology. Both providing a fresh perspective on how we look at technologies as tools and data sources, and therein redefining what we want out of new technologies. This will require that we have a willingness to expand (but not abandon) our current views of "quality data" and "useful data"—adopting instead a view that different data needs do not have the same demands in terms of level or characteristics of "quality." We need also to break the mold in terms of our approaches to problem-solving. Finding solutions to current and future problems need not always be a linear process. In fact, some of the best research and development can occur in the absence of a particular problem at hand that requires solution. Finally, we need to evolve in

terms of our professional self-image, thinking in a broader manner about our professional mission and how we view our role in the world of measurement.

THINKING ABOUT TECHNOLOGY & DATA CAPTURE

As survey researchers, we often view new technologies first as potential "survey-enabling" tools, rather than as data collection vehicles in their own right. We view the technologies as potential platforms for hosting surveys rather than as foundations for collecting new forms of information. Often when confronted with the opportunity to use a new technology we ask ourselves "How can we use technology to conduct a (traditional) survey?" or "How can we use technology to extend or augment a (traditional) survey?" Instead, we should ask ourselves "What are the questions / data elements we need to answer / collect to provide insights into phenomena of interest and how can technology be utilized to acquire that understanding / those data?" In asking the question in this manner, we might well look to utilize various technologies in much different ways.

Framework for Thinking about New Technologies

Step	Nature of Technology for Measurement	Nature of Measurement	Nature of Respondent Involvement	Technology Examples	HSRM Panelist Studies
1	Collection of data by an interviewer/data collector	Recall/ retrospective	Active	CATI, CAPI	J. Morton et al. K. Foster C. Hill
2	Reporting of survey data by a respondent (recall/ retrospective)	Recall/ retrospective	Active	Web surveys; TACASI; mobile surveys (retrospective reporting)	C. Hill R. Moser
3	Reporting of data by a respondent in real-time (active involvement)	Coincidental/ concurrent	Active	Mobile surveys (coincidental reporting); meters/monitors/ applications requiring manual intervention	R. Baker
4	Direct measurement of respondent behaviors in real-time (passive involvement)	Coincidental/ concurrent	Passive	Meters/monitors/applications (running in background); spidering/social media mining	R. Baker

We also need to have a goal in mind for where we want technology to take us. Here we're not talking about a specific technology—such as social media or smartphones, per se—but rather more conceptually from the standpoint of behavior measurement. What are our longer-range goals for measurement and how does technology allow us to reach these goals?

One example of a potential framework is provided in the table on the previous page. Here technology use is viewed as an evolutionary process, with emphasis on who in the interviewer-respondent interaction is aided by technology, the nature of the measurement (recall/retrospective versus concurrent/coincidental) and the type of respondent involvement in the measurement (active versus passive participation). This framework allows us to examine how technologies have been utilized in the past and highlights areas where continued development is required.

According to this schema, the first level of technology use for data collection involves platforms and devices that assist interviewers in the conduct of their tasks. Typically this is the administration of a traditional survey, in which most measurements ask respondents to recall and report on behaviors and attitudes. In this sense, the respondent is required to be an active participant in the measurement process.

Examples of such technology are most forms of computer-assisted interviewing, such as computer-assisted telephone interviewing (CATI) and computer-assisted personalized interviewing (CAPI). The Morton (2011) paper in this section highlights this type of technology utilization, using handheld devices to assist in the conduct of personal interviews in emerging countries. This view of technology use can also apply, however, to more nascent technology platforms, such as Second Life. By utilizing virtual reality gaming environment to conduct interviews or focus group (as is the case with the Foster 2011 paper in this section), technology is put to use to assist the interviewer in reaching and interacting with respondents in a quicker and more cost effective means than via traditional methods.

At the second level, technology is placed in the hands of respondents, assisting them in the conduct of a more traditional survey or data gathering activity. Again the respondent is required to be an active participant in order for data to be captured and the nature of the information collected is usually standard survey questions emphasizing recall. Web surveys, use of computer-assisted self-interviewing (CASI), and even surveys sent to respondents via a smartphone are examples. The Moser et al. (2011) use of a Web-based tool for allowing stakeholders input into the development of the questionnaire for the Health Information National Trends Survey (HINTS) is an example of this type of technology use.

With the third level of technology use, the emphasis shifts to collecting behavioral and attitudinal data at the time it occurs. Rather than asking a respondent to recall their prior behavior, technology can be used to capture these data in-the-moment, concurrent with the activity. The approach still requires active involvement by the participant to record the information, but it allows us to move away from recall-based data capture to more concurrent data collection. Use of Smartphones and customized metering devices for capturing repeated measures throughout the day are examples of such approaches.

Finally, the fourth level of technology involves passive data collection, measuring attitudes and behaviors as they occur but doing so without the need for active respondent involvement. This form of measurement strives to produce the most accurate (by measuring behaviors coincidental to their occurrence) and least biased (by reducing or eliminating the need for respondent action to record the information) data. Meters or applications that run in the background and certain Internet data collection techniques, such as spidering are examples.

Both the Baker (2011) and Murphy et al. (2011) papers highlight potential advances in level 3 and level 4 technologies. But the examples they cite come primarily from outside of the traditional survey research field (e.g., from market or commercial research), a testament to the dearth of research in these areas within traditional survey methods circles. While survey researchers have made substantial progress with level 1 and to some degree level 2 technologies, far less work has been done with level 3 and level 4 technologies. Why is this the case?

THE PROBABILITY PARADIGM

The "classic" survey research approach is built upon the foundation that probability-based samples are required to produce "quality data." Yet, one could argue that while the approach has served survey researchers well in many areas, advancing technology adoption is not one of them. Using a strict "probability-based sample viewpoint," we automatically assess potential technology use within a classic framework of concerns: sample frame, sample coverage, and sample response. In doing so, we allow other design considerations—not necessarily those related to the pros and cons of the technology itself—to drive the decision about whether to use technology and, if so, the types of technology deployed. In other words, we "edit" our thinking about the potential utility of an approach or in thinking about new approaches if we

cannot first determine how to get technology into the hands of an "appropriate sample." For example, we often refrain from deploying a technology where we cannot achieve full or widespread sample coverage. While this may make sense from an individual project perspective, it has the effect of slowing our ability to learn about and harness new technologies in optimal ways. If we are always finding reasons why not to deploy a new technology, how can we ever learn about the potential (positive and negative) of these new approaches?

For technology to advance, we need to identify under what conditions a less than optimal sample might suffice. Put another way, we need to develop a "Science of Convenience"—a set of standards and approaches that allow us to move beyond probability samples *when it makes sense and when such samples simply are not an option*. Rather than view probability/nonprobability in dichotomous terms, we need to bridge the gap by applying scientific rigor where we can and gain a good understanding of when non-probability data can be put to good purpose. The argument here is not to dispense with probability-sampling, but rather to find a way to extend many of the scientific aspects of survey research to improve the quality and reliability of non-probability approaches such that we can continue to deploy, test and learn to optimize new technologies in our data collection efforts.

APPROACHING OUR WORK

How we go about tackling problems can also have an effect on how we view and use technology. Typically, survey researchers are very linear in their approach to problem-solving. Problems are identified first, and then solutions are crafted to meet the challenge or solve the problem. Technology development is, therefore, a captive of this process. For example, most "problems" in the survey world are presented in the form of a request for proposal or identification of an area where data are required. Often there are time and resource considerations guiding the response to this issue or problem. Unless there is a fairly ready-made technology solution available to fill the gap, new technology use is often considered but ultimately dismissed due to cost or time considerations and more "tried-and-true" methods are deployed (or the innovative approach is proposed as an "option").

However, what if we were to break this linear "problem-solution" cycle and take a nonlinear approach. John Kingdon (1995) notes that in the world of public policy, "problems" and "solutions" are often independent of each other. Under certain conditions "windows of opportunity" open and the two can be linked to resolve an issue or set of issues. The survey world can be viewed much the same. When it comes to new technologies, perhaps researchers should look at these in terms of "solutions" even in the absence of an immediate "problem" to solve. With this approach, research focuses on identifying and leveraging the strengths and weaknesses of new technologies such that when a "window" opens there are new technology solutions at hand that can be fitted to the problem. In the end, isn't this the nature of true "research and development"? This not to say that such work occurs in a vacuum. Certainly researchers are aware of the general issues and problems within their field, even if a specific research problem is not the immediate focus. In the classical sense, R&D involves detailed research on solutions (just as much as on problems) in order to understand how best to deploy and optimize the use of various solutions.

R&D in the survey world, however, is becoming an endangered activity. The funding that drove much of the development work in the 1970s and 1980s is now far harder to come by, and when it does, it is usually tied to a very specific need or project. Likewise, the closing of many university-based survey laboratories over the past 10 years has considerably narrowed the range and ability of researchers to conduct pure R&D

efforts. As an industry, it is imperative that we find ways to reignite a broader emphasis on R&D efforts within our field.

We also need to recognize that "innovation" is not an easy enterprise. Why is it that when we ask folks to "think innovatively" or "develop an innovative approach," what we often get are different "flavors" of current approaches? Part of this may be the process we typically use as survey researchers. We often try to "innovate" using the same approaches we use for more routine problem solving. That is, we gather the right "experts," white board the issues and potential solutions, button-up details, cost the project, and propose it to a funder. Companies making true innovative advances—such as Google and Facebook—often do things very differently to help promote innovative thought and approaches. Google, for instance, offers some employees a regularly scheduled set-aside day during which they are relieved of their daily tasks and allowed to indulge in more creative pursuits. Facebook promotes a quick turnaround culture in which employees are encouraged to "fail harder"—that is, unless you've experienced some large failures (and not the kind due to simple incompetence), you're not pushing yourself hard enough. They also take a "think it; program it; modify it" approach to getting new technologies in the field faster. Those that work get modified and optimized; those that do not are dropped, their learnings applied to the next endeavor. To be creative in our uses of technology, we need to adopt more creative solutions to how we think and go about developing such solutions.

WHO WE ARE

Finally, how we drive innovation and utilize new technologies may be, in part, due to how we view ourselves. If our perspective is that of a classical "survey methodologist" or "survey researcher," we may in fact be limiting ourselves to the degree that the "survey" component of those titles drives our self-perception. Perhaps a broader concept—such as "measurement scientist"—would be more applicable and foster a broader sense of purpose within the industry. "Measurement" allows us to focus on what we do best—developing ways of capturing data—but within a broader context. Measurement can be a survey offered via a traditional mode or via a new technology platform, but it can also entail "measurement" through a broader array of new approaches as well. Emphasis on "science" recognizes that we do have certain sets of approaches, guiding principles, and ways of assessing quality that should not be abandoned but rather strengthened and applied within these new realms of data collection.

In the end, we do not need to "change" *per se*, but we do need to expand our reach and in so doing "evolve" our self-perception and the ways in which we go about our roles within the broader industry.

CONCLUSION

That the world continues to change is obvious. However, what might not be so apparent to some is the speed at which this change is taking place. The societies we measure, the tools we use, and even the expectations for the data we gather and insights we provide are changing rapidly. To retain leadership (and some may go so far as to say "relevance") in the area of behavioral and attitudinal measurement, we need to evolve as well. This is not a call to abandon what we know, but rather to find ways to expand into new areas and in so doing broaden the nature of the tools we use. We need to think differently about the world, measurement, our processes, and ourselves. If we are successful, we will open a new set of frontiers in both research technology innovation and health insights.

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SESSION 5 SUMMARY

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URGENCY

In 2004, Tourangeau noted that survey research was something of a bellwether for technological and societal change. Researchers adopted technology fairly quickly to more efficiently conduct traditional surveys (e.g., CATI and CAPI software development and adoption). That is no longer the case. Survey researchers are lagging when it comes to understanding and using new technology and communication platforms. It appears that survey researchers generally have not embraced recent technological tools and platforms. There is a danger that we are not keeping current with how the general population, especially younger generations, communicate. For example, many teenagers use Facebook instead of e-mail. Even if some new methodologies are not implemented immediately and technologies continue to morph (which is inevitable), there is value in better understanding new communication platforms and continuously updating our knowledge and methods to utilize them in appropriate and timely ways.

BARRIERS TO DEVELOPMENT/ADOPTION

Funding of research and development of new technology is a major barrier. Most federal grant processes are too slow for funding research on emerging technologies: the technology is out of date before the grant is awarded. As a consequence, work that is done is generally internally funded. When technologies have been developed, they typically have not been adopted by the federal statistical agencies. One contributing factor seems to be a generally conservative approach due to the official nature of the data being collected/reported. Government agencies need strong proof of concept and impact prior to adoption of new technologies and methods. These conditions make it difficult for organizations that want to innovate to do so.

SELF-CONCEPTUALIZATION: "SURVEY RESEARCHER" VS. "MEASUREMENT SPECIALIST"

Another barrier that was discussed is self-conceptualization as "survey researchers" as opposed to "measurement scientists." The survey paradigm defines what we view as the scope of our work, the design options we consider, and how we think about our mission. The fact that many survey researchers define their role in these traditional terms may preclude exploration of new technologies, such as passive data collection (e.g., screen scraping) and social networking tools. There is also a continued general resistance within the health survey research community to consider nonprobability approaches.

In the discussion, audience members also reflected on the respective roles of the commercial versus academic and federal sectors with respect to adoption of new technology. Commercial researchers often are perceived as the innovators due to the heady competition within the industry. More timely or efficient use of new technologies can help companies distinguish themselves. Academic and federal researchers, by contrast, are seen as providing the necessary scientific foundations for the adoption of new technologies. For example, the scientific community embraced list-assisted sampling, but appears to have been resistant to most technological innovations since then. Over 10 years ago, Couper (2000) challenged the survey research community to investigate appropriate applications of nonprobability samples, and session members remarked that this mission has not been adequately fulfilled.

CONNECTING INNOVATION & SCIENCE

The audience and presenters noted that new technology and media tools are not appropriate, at least not yet, for population inference. But they may be used for interviewer training, questionnaire design, substantive research, anecdotal data, etc. Previously, health survey researchers have been successful in integrating technology as data collection tools within the standard survey design framework, such as using the Web as a supplemental data collection mode. The private sector, by contrast, is undergoing a more extensive adoption of new technologies as both sampling frames and data collection vehicles. Presenters stressed that new technologies are not a replacement of traditional probability-based surveys but need to be embraced and coordinated with traditional methods.

MULTIPLE USES OF SOCIAL MEDIA

As measurement scientists (not just survey researchers), we may be able to identify opportunities for utilizing social media for sampling purposes (frames), passive data collection, contacting respondents, providing information about surveys, and enhancing health outcome measurement by leveraging social network data. Currently, social media vehicles appear less promising for traditional sample frame development than as tools for gleaning new nonprobability-based insights into health-related attitudes and behaviors.

QUESTIONS ABOUT THE QUALITY OF DATA GATHERED FROM NEW MEDIA

Audience members raised a number of questions about the quality of data gleaned from new media. With respect to Second Life research, for example, there are questions about whether people respond as themselves or as the persona of their avatar. On Facebook, some people create social media profiles for nonhumans, particularly their pets. There are also questions about how much Web content collected via screen scrapping is "person generated" versus marketing generated. These kinds of data quality issues need to be addressed so that researchers can better understand the fitness of the data for addressing their research questions.

NONPROBABILITY VS. PROBABILITY SAMPLING

The discussant offered that we need a set of standards and approaches that move us beyond probability-based samples when appropriate. A "science of convenience" would help us to keep pace with technologies that are evolving at "light speed." We need to evolve—not abandon what we know but focus on merging science and new technology.

Members of the audience expressed concerns about moving too quickly towards nonprobability sampling. "Evolution" in this direction generally is seen as being a better model than "revolution." There is skepticism as to whether nonprobability samples can truly serve the needs of federal health survey consumers. Nonprobability samples may not be replicable and are not projectable to a general population. In a probability-based context, researchers have a framework for understanding the various error sources, whereas in the nonprobability context, in a sense, "we don't know what we don't know." In light of these factors, many urge caution in our use and adoption of nonprobability methods.

The discussant challenged the audience to assess what makes convenience samples unreliable, possibly develop calibration solutions, and solve the problems. Even our standard probability approaches have

coverage, nonresponse, and measurement issues to some degree. Recent research by Jon Krosnick and colleagues shows differences between probability and nonprobability methods. Rather than focus on the fact that there are differences, we should evaluate how they are different and improve the nonprobability approaches or, at minimum, identify their fitness for use.

CONCERNS ABOUT PRIVACY, CONSENT, AND ETHICS

The audience also raised concerns about the implications of new media for confidentiality, privacy, informed consent, and data security. For example, can researchers simply collect and analyze Facebook postings, or are additional consent and privacy measures needed? According to one presenter, the market research industry is acutely aware of the gravity of these issues, as companies do not want to provoke legislation that bans data collection of this nature. The industry has a precedent of self-regulation that may ultimately help overcome these issues, but many important privacy and consent details currently are unresolved.

RESEARCH AGENDA

The session discussion pointed to several avenues for future research related to the development and adoption of new technology and communication tools in the health survey research community.

- **R&D Funding.** Innovation would be strengthened and accelerated with fast-track funding opportunities in both the private and public sectors.
- **Promoting a Framework for Fitness for Use.** We recommend that a task force of private sector, public sector, and academic researchers be convened to develop a framework to guide researchers in applying Fitness for Use principles to data collection with new technology and communication tools. This may involve the following:
  - Developing criteria for applying Fitness for Use to research questions
  - Developing evaluation tools to validate Fitness of Use and inform data quality
  - Highlight examples of new technology yielding data that are fit for use on a particular research question and examples of new technology yielding data that are unfit for use
- **Social Network Analysis.** Researchers are encouraged to leverage social media to obtain social network data, which can be used to generate new insights on the links between social connectedness and health status and change.
- **Issue of Replicability in Social Networks**. For studies conducted using a social network where results will be tracked/repeated, researchers may want to consider replicating their methods on multiple networks in order to understand the reliability of the results.
- **Use of Social Media in Early Stages of Survey Design**. There appear to be a number of ways in which new technology, especially social media, can be used to enhance the early stages of the survey process. In particular, researchers are encouraged to explore these media as a way to inform questionnaire design, interviewer training, and possibly their own substantive understanding of the survey topic (e.g., from the patient's perspective).
- **Nonprobability Sampling Frames.** We encourage continued research on how nonprobability sample sources can be used to supplement and/or fill coverage gaps in probability-based designs. These investigations may want to consider the implications of such designs for sampling, coverage, and nonresponse errors.

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