

## **Session 3**

# **Enhancing the Design, Access and Analytical Utility of Federal Surveys through Coordinated Efforts Between Sponsors, Stakeholders and Data Users**



## **Influence of Sponsors, Stakeholders, and Data Users on Design, Access, and Analytical Utility of Census Bureau Demographic Surveys**

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The U.S. Census Bureau is unique among federal statistical agencies because it is simultaneously a sponsor of federal surveys it collects and a collector of survey data for other sponsors. The Census Bureau receives authorization and funding directly to carry out some programs but serves as a contractor to other federal statistical agencies in carrying out other programs. We at the Census Bureau refer to surveys sponsored by other federal agencies as reimbursable surveys, because we are reimbursed for our collection efforts much in the same way as a contractor would be.

The variations in authority and funding sources across surveys have a big influence on how the Census Bureau interacts with other federal agencies, stakeholders and data users. The nature of the interaction and the influence of these groups also varies according to the phase of the survey (design, development, administration, and dissemination), and there are different types of coordination efforts based on the relationship between the parties.

Aside from explicit coordination with agencies, stakeholders and users, there is implicit coordination that occurs as part of the budget process—either during the federal budget cycle or as part of the negotiation of the agreement governing the collection. Reimbursable projects are largely driven by sponsors' desires and budgets. Stakeholder and user input is filtered through the sponsor; and requests are honored if the sponsor agrees, funding exists, and it fits within Census policies and standards and within the goals of the survey. User/stakeholder inputs on Census-sponsored surveys are solicited in variety of forums—including conferences, user mailing lists (electronic or otherwise), and websites. Their implementation is conditioned on funding, as well as on how it fits within Census Bureau policies and standards and the survey goals.

Below, I describe the partnerships formed by the Census Bureau with a variety of government and non-government entities; the constraints faced in the development and refinement of demographic surveys; and the process through which sponsors, stakeholders, and users influence the design, access, and analytic utility of the data.

### **The Census Bureau and Its Partners**

The Census Bureau has four different types of partners in the development and administration of surveys and censuses and in the development and dissemination of data: survey sponsors, Office of Management and Budget (OMB), Congress, and data users.

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<sup>1</sup>This paper reports the results of research undertaken by Census Bureau staff. It has undergone a Census Bureau review more limited in scope to that given to official Census Bureau publications, and is released to inform interested parties of ongoing research and to encourage discussion of work in progress.

*Survey Sponsors:* Many surveys conducted by the Census Bureau are authorized and funded through other government agencies, and the Census Bureau acts as the data collection agent (not unlike other non-government survey institutions). The funding agencies are the sponsors of the surveys and other data collection projects, and the Census Bureau works hand in hand with them to develop the survey and sample design. The Census Bureau oversees and implements the data collection and in some cases handles postcollection data processing and dissemination.

The National Crime Victimization Survey (NCVS) represents an example where the Census Bureau provides design, development, administration, and postcollection processing for the survey, based on funding provided by the Bureau of Justice Statistics. The National Health Interview Survey (NHIS) represents an example of where the Census Bureau is the data collection agent only, with the sponsor (National Center for Health Statistics) providing the sample design and selection, as well as postcollection processing and data dissemination.

These two surveys illustrate two different legal authorities under which the data are collected, which has an influence on how responsive the data sponsor can be to the influence of the sponsors, stakeholders, and users. NCVS data are collected under Title 13 and NHIS data are collected under Title 15.<sup>2</sup> While there are a lot of differences between the two titles, the important ones for this paper are the rules governing disclosure protection and release of data to users. All surveys conducted under Title 13 are subjected to the Census Bureau rules governing disclosure avoidance and surveys conducted under Title 15 are subject to the sponsoring agency legislation. In some cases the rules differ significantly between the Census Bureau and the sponsoring agency and in other cases they do not.

*Office of Management and Budget (OMB):* All surveys conducted by the Census Bureau are subject to OMB clearance and we work with OMB on a continuing basis to ensure the instruments we field do not unduly burden respondents while meeting the statistical information needs of the federal government. For general-purpose surveys sponsored directly by the Census Bureau (such as the Survey of Income and Program Participation [SIPP]), the relationship between the Census Bureau and OMB in content determination is very direct. Requests for clearance are prepared in full by the Census Bureau and submitted directly to OMB. Changes required by OMB for clearance are negotiated between Census and OMB. In addition, OMB may convene interagency working groups to debate the scope of the instrument for a particular survey and how that instrument meets (or does not meet) the agencies' needs.

*Congress:* In some instances, the survey or other data collection instrument is either mandated directly by Congress, or some aspects of its content are required by law (the prime example being, of course, the decennial census). In some of these cases (like the decennial census), we work directly with Congress to develop the instrument and determine the data collection project design. It is not unusual for this process to occur as part of the budget cycle (as is currently the case with the development of the American Community Survey), and the simultaneity of budget setting and survey design is often not conducive to careful, iterative instrument development.

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<sup>2</sup>13 USC Sec. 101; 15 USC Sec. 1517.

*Users:* User needs are preeminent in guiding content and data product development. However, the role of users as Census Bureau partners varies depending on the data collection effort and its sponsorship. Users have more direct interaction with the Census Bureau on Census-sponsored surveys; but their needs have to be weighed against budget constraints, federal government priorities for statistical information, and disclosure limitation requirements of public information. The Census Bureau solicits input from users of Census-sponsored surveys in a variety of formats—such as advisory committees, user groups, and conferences. We also welcome unsolicited comments from users and encourage them to contact us whenever they experience anomalies in Census-supplied information. All of our data products and announcements are accompanied by contact information to facilitate these unsolicited comments.

A user's role in reimbursable surveys is typically as a partner or constituent of the sponsor, although there are exceptions—particularly with hybrid surveys like the Current Population Survey, which has multiple components with different sponsors (including the Census Bureau) under an umbrella reimbursable survey. In the hybrid case, users' needs and comments often do come directly to the Census Bureau, but they also come indirectly through the funding source (or sources). As is true in other instances, the user's needs on reimbursable surveys have to be weighed against the sponsor's needs for the overall program and against budget and disclosure constraints.

## **Constraints**

All efforts are made to comply with reasonable requests for changes or enhancements that conform to a data collection project's purpose and goals but, as noted, there are constraints. Regardless of concerted efforts to coordinate with our partners, there are circumstances when needs cannot be met due to insufficient funds. Given the nature of the budget cycle, these constraints are often unpredictable and are often significant (and sometimes both). This situation often allows the players in the budget process in some instances to be *the* most influential Census Bureau partners.

For example, in response to clear and large demand from agencies and users, the Census Bureau put forth a budget initiative on several occasions to reinstate an overlapping panel design for SIPP. The need for an overlapping panel design was identified as part of a larger recommendation to provide data to support a modernization of the official poverty measure—a recommendation from the National Academy of Sciences, reinforced by prominent researchers, user groups, and federal agencies. The budget initiative was rejected each time it was offered, so the highly sought after design change to SIPP has not been implemented. The Census Bureau remains committed to responding to user and stakeholder needs to provide data to improve the measurement of poverty but cannot comply without significant funds, the absence of which creates a solid barrier to cooperation.

The budget constraint can be minimized, of course, when the stakeholder can fund the enhancement. We recently initiated a project to extend the SIPP sample to target a larger segment of individuals receiving Supplemental Security Income or Social Security benefits, because the requestor (the Social Security Administration) was able to provide financial support for the data collection and was able to select the sample from their administrative records.

A second type of constraint is that sponsor, stakeholder, and user requests cannot be fulfilled if they are not in line with the Census Bureau's mission; if they have a negative impact on the Census Bureau's reputation; if they are not consistent with the production of high-quality data; if they do not address sensitive populations and topics thoughtfully; if they do not comply with Census Bureau policies governing content, development, administration, and testing; and if they do not work well within the larger purpose, scope, and design of the survey or data collection effort. Whenever a request comes in, we work with the requestor to adjust the specifics of the request in an attempt to conform to these constraints, if they do not at the outset.

A third constraint is respondent burden. Overall, of course, there are limits on how much time respondents can be asked to spend responding to federal surveys—which, in turn, places limits on the ability to respond to the needs of sponsors, users, and stakeholders. Often, that means it is difficult to expand lines of questioning that are not directly related to the specific purpose of the survey or to improve the precision of a particular estimate through increased probing of respondents. There are trade-offs in the burden metric, so that one can ask more questions—if the size of the universe for each question is restricted to the point where there is no increase in the time respondents take to respond to the survey, on average.

Once a change is agreed to in principle, it must be “proven in,” which is a fourth constraint. We believe that pretesting is critical to the successful collection of the information needed, as it helps to ensure the instruments used to collect the data do accurately measure the intended concepts. Hence, the Census Bureau has a pretesting policy for data collection instruments that requires all questions to be field and/or cognitive tested before they are fielded in a production survey. The pretesting policy accepts, as a substitute for pretesting, proven success of a particular item in the field in a different context. However, since many requests are for data items that are substantively different from items on other surveys, this policy places limits on the introduction of new questions to meet user/sponsor/stakeholder needs when the cost and time requirements for pretesting exceed allowable limits or available resources.

The other major constraints to responding to user and stakeholders' needs are the protections the Census Bureau imposes on data collected on households. For any data collected under Title 13, we cannot and do not publicly disseminate any information that can be used to identify a respondent. This task of disclosure proofing these data is becoming increasingly difficult, with the recent explosion of publicly available information on individuals and of tools to easily locate and access that information. To protect against disclosure of respondent identities, we cannot issue public microdata files with low levels of geography or that identify unusual demographic or

economic events. If users need these data to carry out the analysis, we cannot respond by enhancing the public data products. We have other options, however, to provide sponsors, users, and stakeholders with what they need, when their requests cannot be fulfilled with public data.

- As noted, sponsors can elect to have data collected under Title 15, so that they can access the full array of information collected. This option is used when the sponsor—rather than the Census Bureau—selects the sample (as is true for the SSA project noted above). Since they already have the identities of the individuals selected into the sample, the identity of respondents selected by the sponsor cannot effectively be protected from the sponsor.
- Another option is to offer data users the choice of submitting a proposal to carry out their work at one of the Census Bureau-run research data centers spread across the U.S. If the proposal is accepted, the researcher can become a special sworn-status “employee” of the Census Bureau and thus be subject to all the laws and penalties for misuse of data. In that case, they are approved to work at a Census Bureau site using more detail than is publicly available. They work under the supervision of Census Bureau staff and can only remove results from the center that meet the Title 13 constraints.
- Finally, users requiring more detail than can be disseminated on a public-use microdata file can request a special tabulation of the nonpublic files and can receive the results in aggregate form (if they meet the Title 13 restrictions).

## **Process**

In spite of the major influence of the budget and the presence of other constraints, the Census Bureau does adjust survey or sample design or postcollection processing systems to meet the needs of sponsors, stakeholder, and users. Sometimes, there is a lot of room for compliance with the request—particularly at the beginning of a long term program or at the point of a major redesign. On most occasions, however, only marginal adjustments are feasible.

To implement requested changes, the Census Bureau must coordinate with all of its partners in the survey, and the process of doing that varies by the type of mandate under which the data are collected. As noted, we have certain standards and policies that impact the relationship with sponsors. There are certain types of information the Census Bureau will not collect. For example, we will not collect information if it requires biological samples from respondents. In those cases, the sponsor will have to decide either to not include those data items or to seek another data collection agent.

In the case of reimbursable surveys, the sponsor’s needs dominate. When a request to change a reimbursable survey comes to the Census Bureau, we work with the sponsor to see if we can refine the collection strategy in response to the request, and to see if we can do so within the budget constraints the sponsor faces. If not, the request is modified or rejected. If so, the final

decision to accept or reject resides with the sponsor, since it is the sponsor who largely determines the scope and major design features of the survey. The sponsor may not agree to the requested change, even if the request falls within the constraints noted above (in which case, the request is rejected). Of course, requests from stakeholders and users may go directly to the sponsors, who have various ways in which they interact with users and stakeholders (interagency or advisory committees, user groups, federal register notices) to gauge the appropriate direction to take for their surveys. In those cases, the changes are requested by the sponsor to the Census Bureau and negotiated as part of the ongoing working relationship between the Census Bureau and the sponsor.

A different process governs any request to enhance or otherwise change legally-mandated items on surveys or censuses. To accomplish change, we make recommendations to Congress based on our understanding of the legal requirements and based on guidance we receive from established advisory committees (whose purview includes that content). Congress will approve (or not) the recommendations and, when they do not, we revise and present new ones until the content becomes agreeable. This effort is largely carried out working with Congressional staff of the various committees that oversee the Census Bureau or have data needs. Stakeholders and users are represented in the process either through the advisory committees or their congressional representatives, and make requests for changes through these groups.

The Census Bureau is always open to (and frequently solicits) suggestions for enhancements to the surveys and projects we sponsor. Census-sponsored surveys have various mechanisms for soliciting input on content and design and for implementing requested changes. The staff maintain a presence at professional meetings and conferences on topics related to our data collection efforts. At these conferences, we often present updates on the status of Census-sponsored surveys and discuss research and other efforts that influence the survey design, execution, or dissemination. The Census Bureau maintains websites for the Bureau as a whole and for individual projects, and those websites provide contact information for individuals who can accept and process requests for changes. The Census Bureau has a marketing services office to encourage familiarity with and use of our products, and to support display and information booths at conferences and other meetings. This office also provides conferences to help users of data, particularly tabular or aggregate data, complete their analysis. The Census Bureau also includes formal notification of pending data collection efforts in the Federal Register for public comment.

Occasionally, a specific Census-sponsored project or survey will initiate a survey of users to determine the most desired content and design features. Some projects have committees of stakeholders (formal advisory committees, technical working groups, and OMB-sponsored interagency groups), through which comments and technical review and evaluations are sought. Interactions with these groups frequently lead to changes in some aspect of the survey or its processes. An example is the American Community Survey, which has formal advisory committees to which it needs to respond, as well as congressional committees and user groups.

At the project level, we often maintain open list serves and/or working groups that tend to be populated by heavy users or those with a strong interest in a particular data collection effort.

These provide forums for discussion of issues, sharing of techniques for understanding or analyzing data, and suggestions for changes. For example, SIPP has a user list serve, an interagency group to review topical modules, and a local users group that meets once or twice a year. The project managers at the Census Bureau will also arrange for periodic meetings with users to solicit input or to announce new products or services. These are convenient forums to gain information about a survey and to provide comments.

In addition to survey-specific groups, the Census Bureau often sponsors, cosponsors, or participates in meetings and seminars focused on specific themes, and these meetings frequently generate suggestions for improvements to both Census-sponsored and reimbursable surveys. The meetings tend to be topic- or function-based but can take on many forms and be sponsored by a variety of different organizations. For example, there are the two interagency committees on nonresponse sponsored by Federal Committee on Statistical Methodology; over the years, there have been Census-sponsored working groups formed by the Association of Public Data Users to discuss Census Bureau data products.

At the moment, the Census Bureau is considering the possibility of establishing one or a series of user conferences for users of microdata from our surveys. This would not overlap with the existing seminars on tabular data, because this series would be restricted to issues unique to using the microdata directly. We expect this series of conferences would yield good suggestions for survey enhancements.

## **Conclusion**

Sponsors, stakeholders, and users have significant influence over the design, access, and analytical utility of Census Bureau demographic surveys. The reimbursable surveys are governed for the most part by the sponsors goals and budgets and the scope of the project is negotiated formally through a contractual arrangement that governs the transfer of funds to the Census Bureau. The U.S. Congress has a great deal of influence over census-sponsored activities, largely through the budget-setting process and through legal mandates for collection of information. The Office of Management and Budget has influence through the clearance process and assessment of the burden of collection on the general population. Users provide both direct and indirect feedback on the analytic utility of the information provided by the Census Bureau, which is then used to guide decisions on data file and survey design and content.

Of course, all requests for enhancements have to be screened to ensure they are consistent with the budget and scope of the survey, as well as Census Bureau and federal guidelines for collection and dissemination of data. These constraints limit the amount of change that can be included, but they do not prevent change altogether.



## **Enhancing the Design, Access and Analytical Utility of Federal Surveys Through Coordinated Efforts Between Sponsors, Stakeholders and Data Users**

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### **Introduction**

Co-ordinated efforts between survey sponsors, stakeholders and data users have been demonstrated to yield synergies that have been quite successful in facilitating enhancements to the design, access and analytical utility of federal surveys. This paper provides several examples of effective co-ordinated efforts in achieving notable survey design and analytic enhancements to a national information resource to inform health policy, the Medical Expenditure Panel Survey (MEPS). Attention is given to the analytical enhancements and design efficiencies introduced to the MEPS as a consequence of the Department of Health and Human Services Survey Integration Plan. Examples are provided of additional content enhancements to the MEPS to support health care quality measurement that were achieved through coordinated efforts. Furthermore, the collaborative efforts between the Agency for Healthcare Research and Quality (AHRQ), the Bureau of the Census, the Bureau of Labor Statistics, the National Center for Health Statistics, CDC, the Centers for Medicare and Medicaid Services and OMB are discussed, with attention given to the design improvements realized and the enhanced state level estimation capacity achieved for the MEPS Insurance Component.

### **Background**

The Medical Expenditure Panel Survey was designed to produce national and regional annual estimates of the health care utilization, expenditures, sources of payment and insurance coverage of the U.S. civilian non-institutionalized population. The MEPS includes a survey of medical providers, to supplement the data provided by household respondents. The design of the MEPS permits both person based and family level estimates. The scope and depth of this data collection effort reflects the data needs of government agencies, legislative bodies, and health professionals for the comprehensive national estimates needed in the formulation and analysis of national health policies. The survey is sponsored by the Agency for Healthcare Research and Quality (AHRQ).

The MEPS collects data on the specific health services that Americans use, how frequently they use them, the cost of these services and how they are paid, as well as data on the cost, scope, and breadth of private health insurance held by and available to the U.S. population. MEPS is unparalleled for the degree of detail in its data, and its ability to link health service medical expenditures and health insurance data to the demographic, employment, economic, health status, utilization of health services, and other characteristics of survey respondents. Moreover, the MEPS provides a foundation for estimating the impact of changes in sources of payment and insurance coverage among various economic groups or special populations of interest, such as the poor, the elderly, veterans, the uninsured, and racial and ethnic minorities (J. Cohen, 1997).

## **DHHS Survey Integration Plan and MEPS Enhancements and Efficiencies**

As part of the Reinventing Government Part II (REGO II) activities, DHHS targeted improvement of the analytic capacity of its programs, filling of major data gaps, and establishment of a survey consolidation framework in which DHHS data activities are streamlined and rationalized. A Survey Consolidation Working Group was charged with developing a consensus plan for meeting these objectives (Hunter, Arnett, Cohen, et al., 1995; Arnett, Hunter, Cohen, et al., 1996).

A major concentration of the Survey Integration Plan was the redesign of the health care expenditure and insurance studies conducted by DHHS, which include the National Medical Expenditure Survey (NMES, the precursor of the MEPS), the Medicare Current Beneficiary Survey (MCBS), and National Health Interview Survey (NHIS). The proposed survey integration plan was designed to achieve significant cost efficiencies by eliminating duplicative efforts and reducing overall respondent burden. Furthermore, the analytic capacities of the component surveys were enhanced because their design features were integrated. To improve survey design capabilities, enhancements such as an ongoing longitudinal survey effort and the capacity to derive State-specific health care estimates were considered. Consideration was also given to including a periodic institutional component in the survey to provide national use and expenditure estimates for the population residing in nursing homes (Hunter, Arnett, Cohen, et al., 1995).

### *Enhancements and Efficiencies Through Survey Integration:*

One attraction of the DHHS Survey Integration Plan was the enhanced analytic capacity to be achieved by linking the distinct surveys through design integration. Use of NHIS as a sample frame for MEPS increased the analytic content of the resultant linked surveys. Through design integration of DHHS surveys, inefficiencies associated with duplicative survey efforts were reduced. Another goal was to reduce survey design costs by implementing a uniform framework for DHHS-sponsored surveys that have overlapping analytic focus with respect to questionnaire content, data editing, imputation, estimation, database structure, and development of analytic files.

By moving to this integrated, annual household data collection effort, DHHS expanded and enhanced its analytic capabilities. The DHHS Survey Integration Plan:

- Retained the design of the core NHIS household interview. This core provides cross-sectional population statistics on health status and health care use, with sufficient sample size to allow for analyses based on detailed breakdowns by age, race, sex, income, and other sociodemographic characteristics. The core also allows the use of data on a broad range of topics currently covered by NHIS;
- Retained the analytic capacity to obtain annual and quarterly population estimates of health care use and the prevalence of health conditions, both for the Nation and for policy-relevant population subgroups;
- Provides the ability to model individual and family-level health status, access to care and use, expenditures, and insurance behavior over the year and examine the distribution of these measures across individuals. The longitudinal feature of MEPS (collecting data

- over multiple years) further enhances the capacity to model behavior over time;
- Provides the ability to relate data from a detailed sample (e.g., MEPS) to a larger sample (e.g., NHIS) to enhance the utility of MEPS for national health account estimation and microsimulation modeling, including disaggregation by age group or geographic area.
  - Provides the potential to yield both national and State-level estimates for marginal costs using the enhanced sample design of the NHIS, which includes 358 primary sampling units;
  - Provides, as a result of the longitudinal aspect of the MEPS integrated data collection effort, an increase in statistical power to examine change or make comparisons over time; the capacity to examine changes over time as well as changes in the relationships among measures of health status, access to care, health care use, expenditures, health insurance coverage, employment, functional limitations and disabilities, and demographic characteristics.

#### *Enhancements to MEPS Household Component*

The original NMES-3 sample design called for an independent screening interview to identify a nationally representative sample and facilitate oversampling of policy-relevant population subgroups. Data collection and training costs associated with this independent screening interview were projected to exceed \$8 million. As part of the DHHS Survey Integration Plan, this separate screening interview was eliminated. Instead, NHIS was specified as the sampling frame for MEPS. NHIS is an ongoing annual household survey of approximately 42,000 households (109,000 individuals) conducted by the National Center for Health Statistics (NCHS) to obtain national estimates on health care use, health conditions, health status, insurance coverage, and access for the U.S. civilian noninstitutionalized population. In addition to the cost savings achieved by substituting NHIS as the MEPS sample frame, the design modification resulted in an enhanced analytic capacity of the resultant survey data. In addition, use of the 1995 NHIS data in concert with the 1996 MEPS data provides additional capacity for longitudinal analyses not available in the original (NMES-3) design. Furthermore, the greater number and dispersion of the sample primary sampling units that comprise the MEPS national sample resulted in improvements in precision over the original design specifications.

#### **Design and Estimation Strategies and Innovations in the MEPS for the Measurement of Health Care Quality**

Efforts are underway in the Department of Health and Human Services towards the development of a national health care quality reporting system. The purpose of the reporting system is to provide an annual profile of the nation's quality of care and to help measure improvements over time. Quality is often defined as meeting customers' expectations. Consequently, the quality reporting system will need to include a comprehensive set of indicators that characterize several dimensions of patient satisfaction and consumer satisfaction with providers, health plans and access to care. This section focuses on the statistical and methodological design strategies and innovations in the MEPS achieved through coordinated efforts between survey sponsors and experts in quality measurement both within DHHS and the research community at large.

*Coordinated Efforts of the AHRQ-MEPS Steering Group to Enhance Survey Design, Analytic Utility and Data Access*

The Medical Expenditure Panel Survey (MEPS) is the only longitudinal, nationally representative survey designed to provide in-depth information on the health care use, expenses, payments and insurance coverage. AHRQ's reauthorizing legislation and data requirements for the National Quality Report (NQR) and the National Disparities Report recently necessitated the implementation of a series of "fast-track" enhancements to the MEPS to permit improved health care quality measurement and studies of access to care at the national level. An AHRQ-MEPS Steering Committee was established to provide recommendations to the Director of AHRQ regarding the most appropriate enhancements to the MEPS content to permit analyses of the relationships between health care quality, outcomes, access, use and cost at the national level; to provide information on the quality of care and patient outcomes for frequently occurring clinical conditions; and to implement design changes to improve the precision of survey estimates through cost effective sample design modifications. From its inception in the Spring of 2000, the Committee members included a wide range of science partners in informing recommended enhancements, and also served to align the MEPS and its products more directly with all the goals of the Agency. All Committee recommendations were implemented rapidly without jeopardizing the effective operation of the MEPS survey. Without their work, it would not have been possible for the Agency to provide information on the relationship between health care quality, outcomes, access, use and cost to department stakeholders including academicians, insurers, employers, the Assistant Secretary for Planning and Evaluation (ASPE), the Office of Management and Budget (OMB), the National Center for Health Statistics, CDC, and the Centers for Medicare and Medicaid Studies (CMS). The scope and depth of the resultant enhanced MEPS data collection effort reflects the needs of government agencies, legislative bodies, and health professionals for comprehensive national estimates necessary for the formulation and analysis of national health policies.

The Committee efforts substantially increased the number and diversity of research users - in and out of AHRQ - in the specification of the MEPS enhancements related to the content, design and direction of the survey. The MEPS data made available for analysis through this Committee's efforts are currently being used to inform questions about the health care quality of the nation. The MEPS enhancements will permit more detailed studies of concern to the Department and the public: the extent to which Americans, and especially children, have access to care; their use of clinical preventive services; their satisfaction with health plans; and their health care quality.

*Design and Content Modifications to the MEPS to Support Quality of Care Analyses at the National Level*

The MEPS healthcare quality enhancements called for a significant household survey sample expansion of individuals with certain illnesses of national interest in terms of patient satisfaction with care received, the quality of the care and the burden of disease. The intent of this enhancement was to permit more focused analyses of the quality of care received for these special populations. In order to move forward with sample design analyses and MEPS questionnaire design modifications according to schedule, it was necessary to finalize the set of medical conditions that would be given special emphasis with respect to health care quality measurement and patient satisfaction.

A set of formal criteria were established to guide the decision making process regarding the selection of the set of medical conditions that were to be given special attention for implementing the planned MEPS healthcare quality enhancements. More specifically, the selection decision was based on an evaluation of conditions using the following criteria:

- Sufficient prevalence to support reliable estimates,
- Availability of diagnostic questions used in other national surveys,
- Accuracy of household reported conditions,
- Availability of evidence-based quality measures, and
- Level of medical expenditures for treatment of the condition.

Based on the review of the criteria under consideration, it was recommended that the following medical conditions be given special attention for implementing MEPS healthcare quality enhancements based on their capacity to meet most or all of the specified targets: Diabetes, Asthma, Hypertension, Ischemic Heart Disease, Arthritis, Stroke and COPD. It should be noted that the selection of diabetes and ischemic heart disease as targeted conditions also cover two clinical areas that are the focus of the forthcoming DHHS Report on Health Care Disparities. A summary of the availability of relevant diagnostic questions, the capacity of households to accurately report these conditions, the availability of evidence based quality measures and the level of medical expenditures for treatment of the conditions under consideration are available from AHRQ.

To further improve the precision of the survey estimates beyond the gains from the increase in geographic areas from 100 PSUs to 195 PSUs, in particular for individuals with at least one of the medical conditions given special attention for implementing MEPS healthcare quality enhancements, a decision was made to increase the 2002 MEPS sample to a total sample of 15,000 households. In addition, the following two sample allocation methods were under consideration for implementing the desired sample increase: 1) the adoption of a uniform sample size increase versus 2) a targeted oversample of individuals with specific conditions. As a consequence of the subsampling method within households adopted in the National Health Interview Survey to obtain medical condition data (the selection of only one adult and, when available, one child to answer the questions related to medical conditions), it was recognized that the implementation of a targeted oversample of individuals with specific conditions would be significantly limited by the constraints of the NHIS design. Consequently, the sample design recommendation was to implement a sample size increase in MEPS that would enhance the representation and precision of the targeted conditions without a targeted oversample. This sample design modification has the following attractions :

- For fixed sample size, it achieves greater precision in national estimates of general population characteristics relative to a targeted oversample
- It required only minimal modifications to the prior MEPS sample selection procedures;

There are minimal additional complexities in the development of MEPS estimation weights. In addition to the improvements in precision for individuals with the targeted conditions, the adoption of this sample enhancement in MEPS for 2002 also facilitated gains in precision for minorities and ethnic groups which support the Department's Initiative to Eliminate Racial and Ethnic Disparities, for adults with functional limitations and for children with special health care needs.

*Inclusion of Additional Questions in a MEPS Self Administered Questionnaire (SAQ) to Measure Quality of Care and Patient Satisfaction:*

The selection of a core set of questions that measure quality of care and patient satisfaction was governed by the need to adopt measures that were carefully tested and validated, to insure the collection of meaningful and reliable information. Consequently, a subset of questions that were developed for the Consumer Assessments of Health Plans Study (CAHPS) were selected for inclusion in a self-administered questionnaire (SAQ) in the MEPS to measure several dimensions of healthcare quality and patient satisfaction. In addition, the Self Administered Questionnaire included the complete set of questions from the SF-12 (Medical Outcomes Study, Short Form) to improve the survey's capacity to measure health status. It also included the set of questions that comprise the EuroQuol 5D (EQ-5D), including the visual analogue scale, to facilitate international comparisons on health status and quality measurement.

*Data Center*

Many MEPS databases include considerably more data that can be made available to the general public because of the constraints of confidentiality guidelines. In order to facilitate the use of such data, while maintaining the confidentiality promised to respondents, AHRQ's Center for Cost and Financing Studies (CCFS) has developed a Data Center, which is a physical space at AHRQ in Rockville, Maryland where researchers with approved projects can be allowed access to data files not available for public dissemination. These data, which are classified as "restricted", contain information that are not released to the public. These data sets may contain geographic variables at a lower level than released for public use, more detailed condition information, or may consist of unedited data base segments not yet prepared for public release. These restricted data sets do not contain information that would directly identify a respondent (name, social security number, street address).

In order to protect the confidentiality of respondents, the physical environment in the CCFS Data Center is monitored. Researchers are allowed access only to the information required to complete their project. Materials cannot be removed from the Data Center until they have been reviewed by specific CCFS staff for disclosure avoidance. This disclosure review is conducted by a CCFS employee with knowledge of the project and is also reviewed by the Data Center Manager. Only summary output (tables, regression equations, parameter estimates) may be removed from the Data Center. Micro data files can not be removed from the Data Center.

## **Coordinated Efforts of the Interagency Committee on Employment-Related Health Insurance Surveys to Enhance Survey Capacity**

The Interagency Committee on Employment-Related Health Insurance Surveys includes the following federal organizations as participants: AHRQ, the Bureau of Labor Statistics (DOL/BLS), Centers for Medicare and Medicaid Services (CMS), NCHS, the DHHS Office of the Assistant Secretary for Planning and Evaluation (ASPE), the Bureau of Economic Analysis, OMB, the Department of the Treasury, and the Bureau of the Census. The purpose of the committee is to communicate and coordinate federal efforts to collect information on establishment-based health insurance. Furthermore, a stated goal is to understand the purpose of each survey, the uses of survey data, the needs of data users, and the gaps in information collected. The Committee's immediate focus was on the BLS sponsored National Compensation Survey (NCS) and AHRQ's Medical Expenditure Panel Survey - Insurance Component (MEPS-IC), with the objective of:

- Investigating the aims of each survey, types of information collected, estimates produced, uses of data for estimation and research
- Assessing similarities and differences in uses of surveys and data collected
- Assessing gaps in data collection and data needs.

The MEPS Insurance Component (IC) consists of two subcomponents, the household sample and the list sample. The household sample collects detailed information on the health insurance held by and offered to respondents to the MEPS Household Component. These data, when linked back to the original household respondent, allow for the analysis of individual behavior and choices made with respect to health care use and spending. The list sample consists of a sample of business establishments and governments throughout the United States. From this survey, national, regional, and State-level estimates (for almost all States each year) can be made of the amount, types, and costs of health insurance available to Americans through their workplace. The Committee's efforts in reviewing the focus of the MEPS-IC and the NCS helped ensure the analytical objectives of the respective surveys were mutually reinforcing and complementary, rather than overlapping.

Based on the coordinated efforts of this Interagency Committee, the Bureau of Economic Analysis uses data from the MEPS Insurance Component in the computation of the health cost component for employer sponsored health insurance coverage for estimates of the US Gross Domestic Product (GDP) and is studying the potential use of MEPS IC data for their State-level measures. Many other Federal offices, such as the Treasury Department, the Joint Committee on Taxation, the Centers for Medicare and Medicaid Services, and the Pension and Welfare Benefits Administration, are frequent users of MEPS IC data and often make special request for specific estimates.

Many of the MEPS IC estimates are at the State-level - making them particularly valuable to both Federal and State agencies. Special data request have been provided to representative agencies from most States. In support of the HRSA State Planning Grant program (that helps State agencies analyze and address the issue of the uninsured), the MEPS IC survey has produced many additional tables of estimates. Some States (Massachusetts, Arkansas, and

Wisconsin) have provided funding for additional MEPS IC sample for their States in order to improve their State estimates for specific years. In the past two years, HRSA has also funded additional MEPS IC sample in many of their grantee States to increase the number of States for which estimates can be made in a given year.

## **Summary**

Over the past several years, the Medical Expenditure Panel Survey (MEPS) data have quickly become a linchpin for the nation's economic models and their projections of health care expenditures and utilization. The enhanced level of detail and analytical content enables public and private sector economic models to develop national and regional estimates of the impact of changes in financing, coverage, and reimbursement policy, as well as estimates of who benefits and who bears the cost of a change in policy. No other national population based survey provides the foundation for estimating the impact of changes on different economic groups or special populations of interest, such as the poor, elderly, veterans, the uninsured, or racial/ethnic groups. This paper has highlighted several examples of effective co-ordinated efforts between survey sponsors, stakeholders and data users, to demonstrate the notable enhancements in design, access and analytic utility for the MEPS that have been adopted to help inform health policy and facilitate health care quality measurement.

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## **Coordinated efforts involving the National Center for Health Statistics and its survey co-sponsors, stakeholders, and data users<sup>3</sup>**

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This paper describes coordinated activities within the National Center for Health Statistics (NCHS), which is part of the Centers for Disease Control and Prevention (CDC), and between NCHS and its survey co-sponsors, stakeholders, and survey data users. Some of these activities are the results of survey integration efforts that began in the previous decade within the Department of Health and Human Services, where survey integration may be thought of as the conscious design and carrying out of surveys so as to achieve synergy between surveys that improves the effectiveness of the surveys. This paper focuses mostly on surveys conducted by NCHS' Division of Health Interview Statistics.

The National Center for Health Statistics has four “data divisions,” defined according to the type of data collected. Vital statistics—administrative data on births, deaths, and other life-related events—are collected by the Division of Vital Statistics from all of the states, and processed and merged into national data bases maintained at NCHS. One product is the National Death Index, a cumulative compilation of information about all deaths in the United States. Collecting national vital statistics requires ongoing consultation and cooperation among the states and NCHS. An example of such cooperation is the development of standard birth and death certificates that improve comparability of the data from different states and facilitate combining and analyzing those data. The standards are reviewed and revised approximately every 10 years, with participation in that process by data users, including recognized experts in epidemiology and public health. For further information on the national vital statistics system, see Freedman and Weed (2002) and references cited therein.

The National Health Care Survey, conducted by the Division of Health Care Statistics, is really a family of sample surveys that gather data on the use of health services and on the characteristics of patients, providers, and facilities involved in health care transactions. These surveys cover hospitals, nursing homes, doctors' offices, emergency rooms, ambulatory care units, etc. One challenge is the goal of creating components of the National Health Care Survey that are mutually exclusive and exhaustive in their coverage of the health care delivery systems. In reality, the boundaries between the different types of health care systems are sometimes blurred, and single individuals commonly utilize two or more of these systems in a given time period. To adapt to rapid changes in health care delivery systems, NCHS is updating its health care survey sampling frames and survey designs, which has involved extensive consultation with experts and data users. For further information on the National Health Care Survey, see Demlo and Gentleman (2002) and references cited therein.

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<sup>3</sup> Presented at the Federal Committee on Statistical Methodology's Statistical Policy Seminar on Challenges to the Federal Statistical System in Fostering Access to Statistics, Enhancing the Design, Access and Analytical Utility of Federal Surveys Through Coordinated Efforts Between Sponsors, Stakeholders and Data Users, Bethesda, Maryland, 2002.

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The Division of Health Examination Statistics conducts the National Health and Nutrition Examination Survey (NHANES), an ongoing series of surveys that originated in 1960. A random sample of subjects answer questions about their health, and they undergo extensive physical examinations in NHANES' specially-outfitted trailers. These Mobile Examination Centers visit communities around the country each year. NHANES managers periodically issue calls for proposed topical material to be covered by the survey. At any given time, intense collaboration occurs among NCHS and some 15-20 collaborators who are co-sponsoring the survey. NHANES also organizes conferences regularly to facilitate communication among survey managers, co-sponsors, and data users. For further information on NHANES, see Berman et al. (2002) and references cited therein.

Interview surveys conducted by the Division of Health Interview Statistics include the National Health Interview Survey (NHIS), the National Immunization Survey (NIS), the State and Local Area Integrated Telephone Survey (SLAITS), and the Joint Canada/United States Health Survey (JCUHS). NHIS is the principal source of information on the health of the civilian, noninstitutionalized household population of the United States. It is an in-person interview survey, covering everyone living in about 41,000 households (about 107,000 persons) each year. NIS is a telephone survey that collects data on immunizations received by children 19-35 months of age from all 50 states and in 28 metropolitan areas. It is co-sponsored by the National Immunization Program in Atlanta and NCHS. SLAITS is a telephone survey mechanism that utilizes the same sampling frame as NIS to conduct topical surveys, either national or state-based. JCUHS is a one-time (2002-2003) bi-national telephone survey covering the United States and Canada at the same time with virtually the same questions. The remaining discussion in this paper will focus on activities involving these DHIS surveys. For further information on NHIS, NIS, and SLAITS, respectively, see Demlo and Gentleman (2002), Zell et al. (2000), and Blumberg et al. (2002), and references cited therein. For further information on JCUHS, see Gentleman (2003).

### **Some coordinated activities between surveys/agencies**

#### *The National Health Interview Survey (NHIS) and the National Health and Nutrition Examination Survey (NHANES)*

Many of the questions on the NHANES questionnaire are also on the NHIS questionnaire. This permits comparative analyses of results from the two surveys for purposes of assessing data quality and for cross-walking between the two surveys. For example, comparisons among NHANES physical examination data, NHANES interview data, and NHIS data are useful because interview data are self-reported or reported by proxy, and are thus prone to more reporting error than are objective physical examination data. Also, NHANES physical examinations can reveal undiagnosed conditions, yielding overall estimates of condition prevalence that should be higher than estimates based on interview data.

#### *The National Health Interview Survey (NHIS) and the National Immunization Survey (NIS)*

The child immunization section of the NHIS questionnaire until very recently contained a subset of questions that asked parents to provide the types and dates of their children's immunizations

and to give NCHS permission to contact the immunization provider(s) by mail to request further information. Having similar questions on both NHIS and NIS permits calibration of NIS estimates to adjust for the fact that NIS, as a telephone survey, cannot cover households without telephones.

*The State and Local Integrated Telephone Survey (SLAITS) and the National Immunization Survey (NIS)*

Fielding NIS requires screening a very large sample of households in order to identify a sufficient number of households with children of an appropriate age for NIS. For example, in 1999, more than 2 million phone numbers were called by NIS in the search for households with age-eligible children, resulting in the identification of about 36,000 such households. SLAITS capitalizes on that effort by utilizing not just some of the families screened into the NIS sample, but also some of the families screened out of NIS, depending on the requirements of the particular SLAITS survey being conducted. Because NIS targets children, SLAITS surveys are often about the health of children. For example, SLAITS' National Survey of Early Childhood Health (NSECH), conducted in 2000 by NCHS and co-sponsored by The Gerber Foundation, the American Academy of Pediatrics, and the UCLA Center for Healthier Children, Families, and Communities, addresses infants' and toddlers' health-related needs, pediatric health care experiences, and child-rearing practices. For further information about NSECH, see Blumberg et al. (2002).

*The National Health Interview Survey (NHIS) and the Medical Expenditure Panel Survey (MEPS)*

Half of the interviewed households from NHIS are reserved for subsequent follow-up by MEPS, which is conducted by the Agency for Healthcare Research and Quality. MEPS collects additional data from some of the NHIS respondents about health care use, health care expenses, and health insurance coverage. Linked NHIS-MEPS microdata, some of which are publicly available on the NCHS Web site, provide short-term longitudinal data for an extensive array of variables.

*The National Health Interview Survey (NHIS) and the National Death Index (NDI)*

Periodically, NCHS staff link NHIS data to the NDI, thus ultimately obtaining information about the underlying and contributing causes of death ("multiple causes of death") of NHIS participants. The linked microdata, which provide longitudinal information that is valuable for outcome analysis, are publicly available on the NCHS Web site.

*The National Health Interview Survey (NHIS) and its supplement co-sponsors*

Currently, a median time of 57 minutes is required to administer the NHIS to a family. In designing each year's NHIS questionnaire, about 20 minutes of this time is reserved for one or more sets of supplementary questions co-sponsored by agencies external to NCHS. The process of selecting, scheduling, designing, testing, administering, processing, and analyzing data from a one-year supplement involves several years of collaboration between NCHS staff and the external co-sponsor. Examples of supplements since 1990 are the Cancer Control supplement, co-sponsored by the National Cancer Institute, National Institutes of Health (NIH) and CDC; questions that track progress of the objectives of DHHS' Healthy People 2000 and Healthy

People 2010 programs; the Child Mental Health supplement, co-sponsored by the National Institute of Mental Health, NIH; Alternative Medicine, co-sponsored by the Center for Complementary and Alternative Medicine, NIH; and a short battery of questions about cell phone use, sponsored by NCHS.

#### *The National Health Interview Survey (NHIS) and telephone surveys*

The 2003 NHIS will contain questions about cell phone use, in addition to its ongoing core questions about the presence of ordinary telephones in the household. This NHIS supplement will provide designers and managers of telephone surveys with needed information to adapt to and adjust for the rapid proliferation of cell phones in the United States. Since many telephone surveys use households with land line telephones as their randomly-selected source of respondents, it is important for designers of telephone surveys to learn about the use of land line telephones versus wireless telephones by household residents.

#### *NCHS and Statistics Canada*

Since 1999, NCHS and Statistics Canada's Health Statistics Division have held an annual Interchange to share information about their many activities of common interest. At one of those meetings, a discussion of the difficulties of comparing estimates from the two countries' respective national health surveys (the NHIS in the United States, and the National Population Health Survey and the Canadian Community Health Survey in Canada) led to a plan to conduct a one-time, joint telephone survey covering both countries at the same time, and using essentially the same questions in both countries. Consequently, the Joint Canada/United States Health Survey began collecting data in late 2002. Respondents in Canada were interviewed in their choice of English or French; respondents in the United States could use either English or Spanish. The two co-sponsoring national statistics agencies will also collaborate in analyzing the data. This bi-national collaborative effort is consistent with the World Health Organization's goal to have a common health survey that will enhance the ability to compare health status across many countries.

#### *The National Health Interview Survey (NHIS) and its responses to DHHS needs and regulations*

NCHS surveys adhere to Office of Management and Budget (OMB) requirements for collection and presentation of information about race and ethnicity. For example, the NHIS question about a participant's race permits specification of more than one race, which is now an OMB requirement, and when administering that question, the NHIS interviewer displays a list of races categorized according to OMB specifications. Another example of NHIS supporting DHHS needs and regulations is the presence on every NHIS questionnaire in recent years of supplementary questions for measuring progress toward reaching objectives of DHHS' Healthy People program.

### **Some interactions between NCHS and data users**

NCHS constantly interacts with users of its survey data. Some examples include the following:

- Release of microdata to the public
- Release and dissemination of analytical results
- Organized systems of responses to requests for information and data

- Maintenance of the NCHS Web site and of listserves
- Holding of workshops on specific surveys
- Sponsorship of the NCHS Data Users Conference
- The NCHS Research Data Center
- Sponsorship of expert panels

The examples above are but a few of the many NCHS activities involving interaction, cooperation, consultation, and coordination within NCHS and between NCHS and its survey co-sponsors, stakeholders, and data users. For extensive information about NCHS and its surveys, and access to selected NCHS microdata files, see the NCHS Web site at <http://www.cdc.gov/nchs/>.

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