ACKNOWLEDGMENTS

AcademyHealth acknowledges the generous support The Robert Wood Johnson Foundation (RWJF) and the Centers for Disease Control and Prevention’s National Center for Health Statistics (NCHS) provided for this Federal Health Data Project. James Knickman, vice president of research and evaluation at RWJF, encouraged us to undertake this project and provided thoughtful guidance throughout the process. Ed Hunter, acting deputy director at NCHS, provided critical support and broadened our understanding of federal health databases.

The Advisory Committee (listed on page A-2 of the appendix) provided the initial direction and outlined the three papers commissioned for this project. Throughout the project we relied on the insights and suggestions made by the authors of the three papers: Dan Gaylin, Marc Berk, John Holahan, Len Nichols, Genevieve Kenney, Lynn Blewett, and Michael Davern.

AcademyHealth thanks the invitational meeting participants for their thoughtful review of the papers and suggestions for how to improve the data needed for research and policy development on coverage and access. AcademyHealth also thanks Jack Needleman and Len Nichols for assisting us with the preparation and review of this summary report. Finally, David Helms, President and CEO of AcademyHealth, thanks his research assistant, Shitang Patel, for his tireless and dedicated work to keep this project on track and to convert participant comments and suggestions into a coherent set of recommendations.
Summary Report

Table of Contents

I. Background and Introduction ........................................................................................................... 1

II. National Health Surveys on Coverage and Access ...................................................................... 3
    A. Federal Household Surveys .......................................................................................................... 5
    B. Foundation-Sponsored Household Surveys ............................................................................... 6
    C. National Employer Surveys ......................................................................................................... 7

III. Weaknesses in Existing Surveys .................................................................................................. 7

IV. Toward Improved Health Data .................................................................................................... 10
    A. Placing Responsibility for Needed Improvements .................................................................... 12

Appendix A—Project Description .................................................................................................... A-1

Appendix B—National Surveys with Health Insurance Data Table ............................................. B-1
I. **Background and Introduction**

Timely, accessible, and reliable federal health data are critical for federal and state policymakers, practitioners, and researchers to monitor trends in the number and characteristics of the uninsured, evaluate past and current coverage and access initiatives, and provide support for the development and implementation of new health coverage and access programs. Multiple departments and agencies within the federal government are responsible for collecting these data. The Census Bureau, part of the U.S. Department of Commerce, is one of the primary sources of insurance data; it conducts two main surveys responsible for deriving health insurance estimates. The Department of Health and Human Services (DHHS) has two major agencies collecting various data for access and coverage: The Centers for Disease Control and Prevention’s National Center for Health Statistics (NCHS) and the Agency for Healthcare Research and Quality (AHRQ). The Centers for Medicare and Medicaid Services (CMS) also collects data related to Medicare recipients, including whether they have supplemental coverage.

The system-wide reform debate of 1993–94 exposed a number of strengths and weaknesses of federal data-collection systems. The primary shortcomings were perceived to be the inability to provide policymakers with reliable estimates of coverage, access, or costs for most geographic areas smaller than the nation, and the time lag between data collection and policy decisions (e.g., 1987 personal health service expenditure data were the most recent available during 1993–94). In addition, the growing methodological preference for longitudinal survey data (following the same individuals for more than one time period) to study important behavioral questions was compelling to many analysts of the rapidly changing health care system.

The agencies within DHHS responsible for collecting health data—especially NCHS and AHRQ (then the Agency for Health Care Policy and Research)—responded to these perceptions admirably within the context of their own missions and survey programs. The National Health Interview Survey (NHIS) now releases estimates of key variables (including insurance coverage) within one year from the date when the survey field work was completed. The annual Medical Expenditure Panel Survey (MEPS) was designed to be longitudinal, nationally representative, and released more quickly through public use files. While there have been improvements in the release of MEPS data, there can be up to two years between when the data are collected in the field and when they are released to researchers and policymakers. It should also be noted that some estimates from MEPS relating to employer-sponsored health insurance are now available for most states every year and all states every three years.

At the same time, state-specific coverage and access estimates were not forthcoming from the redesigned federal surveys, and the important insight that most health care markets are, like politics, local—much smaller than states—was beyond the resources available to federal agencies. Foundations, led by The Robert Wood Johnson Foundation (RWJF), stepped into this breach, and came to play a major role in bolstering federal health surveys. During the last 10 years, foundations have...
partnered with researchers and policymakers to identify additional data needs, fund surveys to fill critical data gaps, and use survey methods that maximized the timely release of data. In addition, the research community has often provided the federal agencies with advice on data-collection methods and on the development of analytic tools and resources to facilitate the use of these data.

The changing priorities and diminished resources of some philanthropies have led to the realization that national foundations cannot supplement federal data sets for policymakers to the extent they have in past years. In addition, with the introduction of the new health privacy regulations, researchers are concerned that their access to federal data sets is becoming more difficult. This changing landscape has prompted health researchers and analysts to call for a re-examination of federal health data-collection strategies.

Overall, there is concern within the health policy and research community that the current surveys do not provide the timely data needed to address policymakers’ questions about coverage and access both at federal and state levels. While there may be enough data available for federal policymaking, there are concerns about the reliability and timely release of the data. Additionally, lack of health data that can be used at the state level may require not only the redesigning of survey samples to be representative of state populations, but also increasing the sample sizes to provide more useful state estimates.

With only modest increases in federal funding anticipated for the near future for agencies that now develop health surveys and statistics, AcademyHealth undertook this project to:

1. Assess the challenges in creating, maintaining, and providing access to federal health databases; and
2. Identify potential strategies and mechanisms to improve and supplement the development and use of federal health databases in order to better inform public and private policymaking.

Funding for this assessment was provided by RWJF and NCHS.

In reviewing the current status of federal health databases and taking into consideration the current funding available from both government agencies and foundations, many participants in the workshop believed that more federal funding and strategic refocusing of current surveys are needed. At the same time, if level or reduced funding is the short-term reality, reconsideration of the wisest use of available resources is in order.

Data from health surveys are used to inform policy and programs in many areas of health and health care. However, for this report, the focus is limited to surveys and data needed to inform policies at the federal and state levels related to health insurance coverage and access to care by various population groups. Other areas in health and health care deserve consideration, and AcademyHealth would welcome
the opportunity to assist the government and foundations in making further assessments of national health data needs.

Based on the advice of an AcademyHealth advisory committee established to guide this project (see Appendix A for a list of members), the following three papers were commissioned for this initial assessment of data related to health insurance coverage and access (at federal and state levels):

1. Dan Gaylin and Marc Berk. “National Vision of Federal Health Data: Past, Present, and Future.” This paper summarizes efforts to-date to chart a vision for future improvements in federal health databases and discusses implications from these prior exercises for making subsequent improvements.
2. John Holahan, Genevieve Kenney, and Len Nichols. “Toward a Federal Survey of Health Insurance and Coverage to Access.” This paper identifies critical gaps in the current federal surveys for insurance coverage and access to care, and suggests possible options for how these gaps might be addressed.
3. Lynn Blewett and Michael Davern. “State Decisions to Supplement Federal Data on State Health Insurance Coverage Estimates.” This paper highlights the important needs for state- and community-level data and discusses options for how these needs might be addressed.

This summary report is based on the three commissioned papers and deliberations on these papers at the invitational meeting held on June 16, 2004. Participants in this meeting included representatives from federal agencies and foundations responsible for the national surveys, and federal and state health policy officials who use these data in developing coverage and access policies and programs.

The primary purpose of the meeting was to stimulate discussion and explore possible changes and improvements needed in federal health data related to coverage and access. While the meeting was not structured to yield a consensus on specific recommendations, it was intended to capture “promising approaches” that, if implemented, would lead to needed improvements. The invited participants were provided the opportunity to review and comment on this meeting summary. See Appendix A for list of participants at the invitational meeting.

II. National Health Surveys on Coverage and Access

Since NCHS was established in 1960, myriad changes have been made in health surveys and statistics to bolster the overall federal health database for access, coverage, and state-specific needs. There have also been a number of efforts to address both methodological and organizational/structural issues in federal health statistics, including survey integration/consolidation, decision-making and coordination mechanisms, and efforts to outline a vision for health statistics.

DHHS has had several major initiatives to create a strategic framework for the collection of data on coverage and access. Efforts during the 1970s at NCHS encouraged important modifications in NHIS and stressed the importance of linkage
across major DHHS data collections. Collaborations between NCHS and the National Center for Health Services Research (now AHRQ) led to the creation of the predecessor survey to MEPS.

In 1995, all federal agencies were strongly encouraged to develop collaborative relationships that would streamline government and improve performance. Further work on survey integration undertaken by NCHS and the DHHS Data Council was incorporated into the 2002 report, titled, “Shaping Health Statistics Vision for the 21st Century.” These efforts had common underlying themes. DHHS needs to have balance in its survey programs in order to meet a wide range of needs within DHHS as well as the broader health community. Survey integration offered major opportunities to leverage assets and obtain better data within reasonable cost constraints. Policies were needed to protect privacy while also ensuring access to data.

While clear progress has been made, there is still much to be done. Survey integration has rarely lead to survey consolidation. While increased investment in overall data collection is essential, ongoing surveys should be subject to the same type of scrutiny as new initiatives. The Department must also be ready to face new challenges that make it more difficult to collect data, especially by telephone.

There has been very minimal investment in methodological research. Major efforts should be made to conduct research that will reduce non-response and measurement error. To ensure objectivity, some evaluation funds should be available to non-federal researchers. Finally, more aggressive efforts should be made across agencies to focus on complementarities and avoid the duplication and competition that adversely affect our ability to meet the needs of policymakers.

In summary, as noted in the Gaylin-Berk paper, these methodological assessments have addressed the following issues:

- Linking federal health data sets;
- Trade-off between the timely release of data and producing highly reliable data;
- Use of emerging technological tools for surveillance; and
- Need for increased investment in survey methodological research.

A number of national surveys focused on insurance coverage and access to care have been conducted by federal agencies and national foundations. This next section briefly describes these surveys and notes their key strengths.
A. Federal Household Surveys

The following household surveys are conducted by the federal government to address health issues related to insurance coverage, access to care, and state-specific needs:

- **Behavioral Risk Factor Surveillance System (BRFSS)**
  The BRFSS is designed to monitor trends on preventable health conditions and behavioral risk factors that are related to injuries and chronic and infectious diseases in the adult population. Strengths of the survey include state-specific and local information for adult populations.

- **Current Population Survey (CPS)**
  The primary purpose of the CPS is to collect monthly employment and unemployment statistics, with a secondary purpose (demographic supplement of the CPS) of collecting information on insurance coverage. Major strengths of the CPS include large sample size, timely release of data, consistent source of information across years, high response rate, state-specific estimates for all states, and critical socioeconomic information.

- **Medical Expenditure Panel Survey – Household Component (MEPS-HC)**
  MEPS provides comprehensive information on health care use and expenditures (including sources of payment), access to care and insurance coverage. Conducted annually, MEPS-HC has several strengths, including detailed annual and two-and-a-half-year longitudinal information on health care utilization, expenditures, health insurance coverage and sources of payment, access to care, as well as health status, health care quality, functional limitations, and chronic conditions.

- **National Health Interview Survey (NHIS)**
  NHIS is used to monitor trends in illness, disability, access to care, and utilization of care. As the major source of information on health, the strengths of the survey include high response rate, detailed information on utilization and access to care, and relatively timely release of data.

- **State and Local Area Integrated Telephone Survey (SLAITS)**
  As an example of federal-private collaboration, this survey—for various sub-populations—has been conducted by NCHS and funded by non-government and non-profit organizations. Designed as a “buy-in mechanism,” the survey is targeted to gather state-specific health information in response to the lack of state- and locality-specific designs of national surveys. In fact, however, almost all of the funding to date has come from the federal government. The survey gathers information on children and sub-populations of children.
Survey of Income and Program Participation (SIPP)
SIPP is a periodic (not annual) survey designed to collect data on income, labor force participation, and program participation. Strengths of SIPP include longitudinal monitoring of individuals, which permits testing for the effectiveness of current programs.

See Appendix B for a more detailed description of the major national surveys that provide health insurance data.

B. Foundation-Sponsored Household Surveys

Over the last two decades, as shortcomings in federal health data became more apparent, especially as states were developing policies and programs to address health coverage and access issues, national foundations sponsored surveys to complement or supplement federal surveys. One key objective of these surveys was to provide state-specific estimates on health insurance coverage. In addition to the surveys cited below, The Robert Wood Johnson Foundation also funded in the early 1990s state-specific surveys of households and employers for its State Initiatives in Health Care Reform Program.

As mentioned earlier, with reduced funding and changing priorities, national foundations are not expected to continue funding these major surveys on an ongoing basis.

- Community Tracking Household Survey (CTS)
  Aimed at providing community-level estimates and funded by The Robert Wood Johnson Foundation, the CTS provides national estimates as well as information for 12 metropolitan communities. The strengths include point-in-time estimates as well as all-year uninsurance, information on access to care, utilization, and out-of-pocket spending.

- National Survey of America’s Families (NSAF)
  With the purpose of providing national estimates as well as state-specific information for 13 diverse states that account for a large share of the nation’s population, the survey provides detailed information on health insurance coverage, access to care, employment, income, education, housing, and other related health issues for both adults and children. Besides the state-specific information, the strengths include point-in-time estimates of the uninsured. The survey was funded collaboratively by a number of foundations, including RWJF and the Annie E. Casey Foundation.
C. National Employer Surveys

Since the majority of Americans get their coverage at the workplace, researchers and policymakers have also sought health insurance information from the following employer surveys:

- AHRQ Medical Expenditure Panel Survey—Insurance Component (MEPS-IC)
  The Insurance Component of MEPS is an employer survey (of establishments) and provides data on estimating firm-level decision-making in providing insurance to their employees. Its primary strengths are the quality and reliability of the data.

- Kaiser Family Foundation/Health Research and Education Trust (KFF/HRET)
  The Kaiser Family Foundation in collaboration with the Health Research and Education Trust conducts another employer survey, collecting information from firms of more than two workers. The timely production of data is its strongest characteristic.

III. Weaknesses in the Existing Surveys

Ultimately, survey data should be used effectively to inform policy that improves health and health outcomes. The invitational meeting participants generally agreed that our national surveys should provide not only information on who has what coverage, but also on how that coverage translates into access to services and ultimately into improved health outcomes. However, it is widely recognized that establishing causation from coverage to outcomes requires both survey data and targeted behavioral research. As highlighted above, prior enhancements have improved our ability to answer the critical questions facing federal and state health policymakers. Each of the current national surveys has been designed to meet a specific purpose, and together they provide a fairly comprehensive view of the level of coverage and access across diverse populations at the national level, but provide limited information for states and localities.

Given anticipated reductions in foundation funding to supplement national surveys, the participants in our invitational conference were concerned that the present combination of surveys do not meet the current needs of federal and state policymakers.

The three commissioned papers and discussion at the invitational meeting reviewed current and emerging issues with federal health surveys. There was broad consensus that the following issues need to be addressed, although participants were not all of the same mind regarding how these issues might be resolved. The weaknesses identified are grouped below into the following six categories:
(1) **Gaps in current surveys produce contradictory estimates of the number of uninsured for how long they have been uninsured.**
Confusion over the number of uninsured and whether the uninsured have lacked coverage for the whole year is detrimental to the policy process and stems from the existence of multiple surveys and estimates using different time period reference points and survey methodologies. Consensus on how best to measure the number of uninsured for specific and policy-relevant time periods is an essential objective. With multiple household surveys using different survey designs and samples, it is not surprising that they produce different estimates of the number of uninsured and the length of time they are uninsured. Policymakers at both federal and state levels are often quite frustrated by these differences, which, in turn, can undermine the degree to which they accept the findings.

(2) **Data are not uniformly released in a timely manner.**
Foundation-sponsored, telephone-based surveys released data considerably faster than the federal norm in the mid-1990s. Federal point estimates are now released more rapidly for the nation using the CPS, NHIS, and MEPS and for the states using the CPS. When the Census Bureau releases the CPS estimates, it also releases the full public use file. The public use files for NHIS and MEPS that provide researchers the needed detail to make their own cross-tabulations using income data, labor force data, and health data are not released for at least one year after the year for which the data are collected. This delayed release of these public use files forces health policymakers to make decisions without having the most current relevant and detailed data.

(3) **Geographic subunit estimates are still largely unsatisfactory.**
State and local estimates were the focus of the larger foundation-supported surveys that have now been discontinued (the NSAF and CTS), and thus merit re-examination in any comprehensive assessment of the adequacy of current federal health data strategies. For example, the RWJF-sponsored 1993 household and employer surveys provided state-specific estimates for 10 participating states, but have now been discontinued.

States are not satisfied with CPS-based state-level estimates, and no one releases sub-state estimates on a systematic basis, despite the fact that many analysts agree that health markets in which most insurance is purchased are indeed local, as are the safety nets that the uninsured use.

Given this need, most states used recent funds provided under their Health Resources and Services Administration State Planning Grant Program to conduct one-time state surveys that would provide regional and/or county estimates. The continued inability of federal health surveys to provide sound estimates for all states and even regional and local estimates is a major concern among policymakers and needs to be addressed. Small-area methods, which use national data on the uninsured, have not proven satisfactory to state and local policymakers.
(4) **Survey content is insufficient.**

Though survey content is considered largely satisfactory in total, some participants argued for increasing content on some surveys, especially as it relates to detailed components of income, which would permit program eligibility determinations to be made and to assess the actuarial value of benefit packages. Participants acknowledged that certain aspects of health and health care may be beyond the reach of survey methods, and that researchers will need to find more innovative means (such as targeted research or case studies) of obtaining such information.

(5) **Survey methodological research is inadequate.**

Research on survey methodology has not received sufficient funding priority. Optimal use of different modes of data-collection needs to be explored in a world of limited data-collection resources. Many participants believed that research on response rates and content should now be given a higher priority. Among many important issues that need to be researched are use of surveillance tools (for example, moving from the Random Digit Dialing land line telephone survey to including cell-phone-only households) and making effective use of Web-based surveys in mixed-mode demographic research. Other examples of trade-offs in survey design and methods, which need to be addressed during the re-examination of the national health databases, include, but are not limited to:

   a. Survey sample size vs. survey content.
   b. Length of the surveys (when determining response rates).

(6) **More mutually reinforcing research and surveillance efforts are needed.**

Research on how specific key policy questions are best addressed via targeted or investigator-initiated research, through survey data-collection efforts, and more effective interface, have also received insufficient funding priority. This could extend to whether the policy process would be better informed from annual expenditure data by a lengthening of the time period covered by the longitudinal panels in MEPS or by redirecting some of the survey funding for targeted research and less frequent collection of expenditure data.
IV. Toward Improved Health Data

The following section presents possible approaches or solutions to the issues highlighted above. These suggestions are based on the commissioned papers and our discussion of these issues at the invitational meeting. In the spirit of our meeting, we offer this summary of promising suggestions with the hope that it prompts those responsible to study these further and make changes as appropriate to meet the identified needs.

Scope and Integration of Current Surveys

1. Formulate a “map” of all national surveys pertaining to insurance coverage estimates, access to quality care, and state-specific health data.
   a. Identify duplications in the “map.”
   b. Identify areas for specialization, especially for state-specific data and local-level data.

2. Do a comprehensive assessment of the analytical value added from the inclusion of comparable measures of health insurance coverage across the respective surveys. Given limited total federal data-collection resources available and the need for sub-national coverage and access estimates, which are linked to good income data, some participants suggested that some redundancy might now be eliminated and savings from this reduction in duplication be used to produce better sub-national or state estimates.

3. It is important to realize that the encompassing content of all federal surveys is very well defined. The problem is that one survey has very good content in area X but not Y and another survey has terrific content concerning Y but nothing on X. Consequently, the following general steps should be taken for appropriate integration of the surveys:
   a. Identify the most essential items to put together in one instrument (this will include design features like a panel survey or state-representative survey).
   b. Establish “wish list” for items to add to existing surveys. Examples might include adding point-in-time insurance coverage in the CPS and adding more detailed income information on NHIS.

Specific Improvements in Current National Surveys

4. Release the data in a more timely manner to help policymakers make decisions in real time.

5. Provide states with better state and local estimates.
   a. Consider increasing sample size of at least one national survey in order to obtain better state estimates.
b. Explore developing partnerships with states and foundations (e.g., SLAITS, “mini-MEPS”) to address these needs.

6. Improve content.
   a. Insurance
      i. Collect sufficient information to produce point-in-time insurance estimates and annual uninsurance.
      ii. Collect information on the type of coverage provided to those surveyed.
   b. Income
      i. Gather detailed income information to produce reliable estimates of income to permit program eligibility status to be assigned correctly. Income data should be coupled with sufficient socioeconomic detail to permit assignment to actual health insurance units.
   c. More detailed data on access, use, and out-of-pocket spending.

Increase Investment in Methodological Research

7. Strive to attain the balance between surveillance and research (i.e., how much we rely on routine surveys vs. periodic and more detailed research studies). It is imperative for the federal government to recognize and consequently fund both.

8. Increase funding for targeted or investigator-initiated research projects in survey methodology.

Increase Integration and Coordination among Agencies

9. Recognize that each agency has its own strengths and weaknesses, and use the strengths from each to form more efficient and reliable federal health database.
   a. For example, AHRQ (which conducts MEPS) emphasizes highly reliable estimates, and while timeliness has improved, there are still frustrating lags in access to key data for policy purposes (e.g., for premium data from MEPS-IC and full-year coverage data from the MEPS-HC). On the other hand, the Census Bureau, which conducts the CPS, produces timely data, but lacks detailed information on access and use of health services. To effectively inform federal decisions on detailed and sustainable policies, some redesign is needed to attain both accurate (by asking the more appropriate questions) and timely data.

10. Increase inter-agency coordination mechanisms.
    a. Though significant improvements have been made in coordination efforts (especially between AHRQ and NCHS), further coordination is required within DHHS as well as between departments, possibly with the DHHS Data Council at the helm in improving and bolstering
federal health statistics and surveys. Since the DHHS Data Council does not include the Census Bureau, the Office of Management and Budget could lead the coordination effort for all federal agencies, as it did with surveys of employer-provided health insurance.

A. Placing Responsibility for Needed Improvements

This section summarizes possible actions that foundations, the federal government, and states might take to address these issues and make needed improvements in national data related to coverage and access.

1. Foundations

   a. Commission a group or task force (possibly convened and led by AcademyHealth) to examine and write a comprehensive assessment of the U.S. health care system’s data needs, explaining which of those needs should be met at the federal level, and outlining an action plan for transforming existing surveys to make it happen. Ideally, this Task Force would collaboratively work with the DHHS Data Council.

   b. Fund data user centers to facilitate use of federal health data using models currently used by the Census Bureau and NCHS.

   c. Continue to conduct opinion surveys.

   d. Fund survey add-ons.

      i. Instruments for state-specific needs

      ii. Other targeted special surveys (population- or community-based)

   e. Do more research on survey methodology; use opportunities for investigator-initiated research on survey methodology.

   f. Provide support for users to conduct research with federal health data.

   g. Provide funding for technical assistance to states while implementing add-on surveys or other federally supported surveys.

   h. Support further development of non-survey data (e.g., claims, medical records, registries).

2. Federal Government

   a. Formulate a “map” of all national surveys on coverage and access.

      i. Identify duplications in the system and potential areas for specialization.

      ii. Disseminate this “map” to appropriate stakeholders.

   b. Allow for/require further inter-agency efforts in increasing survey integration to:

      i. Avoid duplication; and

      ii. More efficiently use the limited resources available.

   c. Address needs for state-level and local-level policymaking through modifications to sample designs, collecting additional sample to enable smaller area estimates, and geo-coding in all federal surveys, as well as
developing strategies for facilitating or supporting data collection by states or other entities to meet their unique needs.

d. Increase responsibilities of the DHHS Data Council.
   i. Establish an ongoing mechanism for the Council to attain input from private producers and users of data, states, and other public and private stakeholders.
   ii. Establish an annual report from the Data Council that could be made public. This will force outside scrutiny of choices that DHHS is making.

e. Design incentives and flexibility for enhanced federal-state partnerships.

3. States

   a. Use partnerships with the federal government and foundations to conduct special focused surveys and/or add-ons to the national surveys to provide state and local health data.
   b. Develop adequate state capacity to analyze the existing federal and state data for state and local needs assessments and program evaluation.
Appendix A: Project Description

Purpose

The purpose of this project is to: (1) assess the challenges in developing, maintaining, and providing access to federal health databases, and (2) identify strategies for improving and supplementing federal health data in order to better inform public and private policymaking.

Background

Health data collected by the federal government are a vital resource for the nation’s health and well-being. These data are used by health services researchers to address critical issues affecting health and health care.

Over the past two decades, federal agencies have increased the breadth and detail of data collected and now maintain a number of important national databases used by health researchers and policymakers, including:

- Medicare Current Beneficiary Survey Series, CMS
- Healthcare Cost and Utilization Project, AHRQ
- Medical Expenditure Panel Survey, AHRQ
- National Health Care Survey, NCHS
- National Health Interview Survey, NCHS

Foundations have played a major role in bolstering federal efforts by partnering with researchers and policymakers to identify additional data needs and funding surveys to fill critical data gaps. In addition, the research community has often worked with the federal agencies to advise on data collection and on the development of analytic tools and resources to facilitate the use of these data. Given the changing priorities and resources of some philanthropies, national foundations that have been leaders in data development to date are not expected to be able to supplement federal data sets to the extent they have in past years.

With the introduction of the new health privacy regulations, researchers are concerned that it is becoming more difficult for them to access federal data sets. AcademyHealth undertook this project, funded by The Robert Wood Johnson Foundation and the National Center for Health Statistics, because of the need to strengthen and supplement federal health databases to improve their usefulness for policymakers, practitioners, and health services researchers.
Advisory Committee

The Advisory Committee, comprised of senior researchers in the federal government and private sector as well as foundation staff, provided input on the scope and process for this project. This Committee outlined three papers to be commissioned and provided to participants prior to the meeting to advance and facilitate an informed discussion, and made recommendations on who should be invited to the meeting.

<table>
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<th>Advisory Committee Members</th>
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| **Steven Cohen**  
Director, Center for Cost and Financing Studies, Agency for Healthcare Research and Quality |
| **Dean Farley**  
Vice President, Health Policy and Analysis, HSS, Inc. |
| **Liz Fowler**  
Chief Health and Entitlements Council, Senate Finance Committee (Minority) |
| **John Holahan**  
Director, Health Policy Center, Urban Institute |
| **Edward Hunter**  
Associate Director for Planning, Budget, and Legislation, National Center for Health Statistics |
| **James Knickman**  
Vice President, Research and Evaluation, The Robert Wood Johnson Foundation |
| **Len M. Nichols**  
Vice President, Center for Studying Health System Change |
| **Edward Perrin**  
Professor Emeritus, Department of Health Services, University of Washington |
| **Dean Rosen**  
Health Policy Advisor, Office of the Senate Majority Leader |
| **Diane Rowland**  
Executive Vice President, The Henry J. Kaiser Family Foundation |
Discussion Papers

The following three papers were commissioned for the Invitational Meeting:

- **National Vision of Federal Health Data**
  This paper summarizes the federal efforts made to date to provide a strategic framework for federal data collection, including implementation and results of these efforts. The paper also highlights successes/failures of these efforts to provide strategic direction for improvements in federal data.
  Authors: Dan Gaylin and Marc Berk.

- **Toward a National Survey of Insurance Coverage and Access to Care**
  After discussing what policymakers need to know about coverage and access to care for households and employers, the paper assesses the data requirements needed for targeting incremental coverage expansion strategies and for analyzing the costs of more comprehensive reform proposals, including universal coverage. The paper focuses on how existing surveys match up with these analytic needs and outlined what an ideal survey might look like for both households and employers. It also notes how existing surveys might be modified to achieve this “ideal.”
  Authors: John Holahan, Len Nichols, and Genevieve Kenney.

- **State Decisions to Supplement Federal Data on State Health Insurance Coverage Estimates**
  This paper highlights the following three questions states face related to using existing federal surveys or conducting state-specific surveys. Specifically, (1) Why did states believe they needed to do their own surveys? (2) What did the states learn from state-specific surveys? and (3) How can state needs for more specific data be met in the future?
  Authors: Lynn Blewett and Michael Davern.

**Project Invitational Meeting**

With the help of the Advisory Committee, AcademyHealth developed a list of prominent federal and state policymakers, producers of health data (federal agency representatives and foundation executives) and researchers with expertise in health data and its use to inform coverage and access policies. The following individuals participated in this meeting:

Linda Bartnyska, Chief, Cost and Quality Analysis, Maryland Healthcare Commission

James Baumgardner, Deputy Assistant Director, Health and Human Resources Division, Congressional Budget Office

Mark Berk, Vice President and Senior Fellow, National Opinion Research Center
Lynn Blewett, Principal Investigator, State Health Access Data Assistance Center. Lynn Blewett is also Associate Professor in the Division of Health Services Research and Policy at the University of Minnesota.

Joel Cantor, Professor and Director, Center for State Health Policy, Rutgers, The State University of New Jersey

Aaron Catlin, Office of Actuary, Centers for Medicare and Medicaid Services

Michael Chernew, Associate Professor, School of Public Health, University of Michigan

Deborah Chollet, Senior Fellow, Mathematica Policy Research, Inc.

Steve Cohen, Director, Center for Financing, Access, and Cost Trends, Agency for Healthcare Research and Quality

Joel Cohen, Director, Division of Social and Economic Research, Agency for Healthcare Quality and Research

Michael Davern, Research Associate, State Health Access Data Assistance Center. Michael Davern is also Assistant Professor in this division.

Dean Farley, Vice President, Health Policy and Analysis, HSS, Inc.

Elliot Fisher, Professor of Medicine, Dartmouth Medical School

Daniel Gaylin, Senior Vice President, Health Survey, Program and Policy Research, The National Opinion Research Center

David Helms, President and CEO, AcademyHealth

John Holahan, Director of Health Policy Research, The Urban Institute

Ed Hunter, Associate Director for Planning, Budget, and Legislation, National Center for Health Statistics

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James Knickman, Vice President of Research and Evaluation, The Robert Wood Johnson Foundation

Doris Lefkowitz, Director, MEPS, Agency for Healthcare Research and Quality

Katie Levit, CMS (Retired)

Amy Lischko, Director, Massachusetts Department of Health Care Finance

Denise Love, Director, National Association of Health Data Organizations
Robert Mills, U.S. Census Bureau

Jack Needleman, Associate Professor, Department of Health Services, School of Public Health, University of California, Los Angeles

Len Nichols, Vice President, Center for Studying Health System Change

Michael O’Grady, Assistant Secretary of Planning and Evaluation

Diane Rowland, Executive Vice President, The Henry J. Kaiser Family Foundation

Kevin Ryan, Program Director, UAMS, Department of Pediatrics, Arkansas Center for Health Improvement

Ed Sondik, Director, National Center for Health Statistics

Gail Wilensky, John M. Olin Senior Fellow, Project HOPE

Wu Xu, Utah Department of Health, National Association of Health Data Organizations

Stephen Zuckerman, Principal Research Associate, Health Policy Center, The Urban Institute
## Table 1.3 Current Features of Six National Surveys With Health Insurance Data

<table>
<thead>
<tr>
<th>Features</th>
<th>Current Population Survey</th>
<th>National Health Interview Survey</th>
<th>Medical Expenditure Panel Survey</th>
<th>Survey of Income and Program Participation</th>
<th>Community Tracking Survey</th>
<th>National Survey of America’s Families</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Survey Characteristics</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Organization managing the survey</td>
<td>Census Bureau</td>
<td>National Center for Health Statistics</td>
<td>Agency for Healthcare Research and Quality</td>
<td>Census Bureau</td>
<td>Center for Studying Health System Change</td>
<td>The Urban Institute</td>
</tr>
<tr>
<td>Survey Design</td>
<td>March supplement is a cross section$^a$</td>
<td>Cross section</td>
<td>Panel, five interviews over 2 years</td>
<td>Panel, every 4 months over 3-4 years</td>
<td>Cross section</td>
<td>Cross section</td>
</tr>
<tr>
<td>Mode</td>
<td>In person and telephone</td>
<td>In person</td>
<td>In person and telephone</td>
<td>In person and telephone</td>
<td>Telephone, supplemented in person</td>
<td>Telephone, supplemented in person</td>
</tr>
<tr>
<td><strong>Sample Design</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Universe</td>
<td>Civilian noninstitutionalized population</td>
<td>Civilian noninstitutionalized population</td>
<td>Civilian noninstitutionalized population</td>
<td>Civilian noninstitutionalized population, excluding Alaska and Hawaii</td>
<td>Civilian noninstitutionalized population under age 65</td>
<td></td>
</tr>
<tr>
<td>Sample frame</td>
<td>Area probability</td>
<td>Area probability</td>
<td>NHIS</td>
<td>Area probability</td>
<td>Random-digit dialing (supplemented by area probability)</td>
<td>Random-digit dialing (supplemented by area probability)</td>
</tr>
<tr>
<td>Sample size</td>
<td>50,000 households</td>
<td>130,000+ people</td>
<td>Varies around 40,000 households</td>
<td>15,000-35,000 people$^b$</td>
<td>60,000 people</td>
<td>44,000 households 10,000 people</td>
</tr>
<tr>
<td>Oversampling</td>
<td>Hispanics</td>
<td>Blacks, Hispanics</td>
<td>Blacks, Hispanics, disabled, low income, high expense, elderly</td>
<td>Low income</td>
<td>For community-specific estimates</td>
<td>For state-specific estimates, low income</td>
</tr>
<tr>
<td>Individual data</td>
<td>All members of household</td>
<td>Health insurance, all members of household; some topics; one adult and one child</td>
<td>All members of household</td>
<td>All adult members of family insurance unit, one child per unit</td>
<td>All states 27 states</td>
<td>Some states 60 communities 13 states</td>
</tr>
<tr>
<td>Location-specific estimates</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td><strong>Health Insurance Questions</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Timeframe</td>
<td>Since start of calendar year</td>
<td>Time of interview, throughout year, ever in year</td>
<td>Last 4 months, monthly</td>
<td>Time of interview</td>
<td>Time of interview</td>
<td></td>
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<tr>
<td>Respondent</td>
<td>Household informant</td>
<td>One person familiar with family’s health coverage</td>
<td>Family informant</td>
<td>Self-reporting for adults (15+)</td>
<td>Family informant</td>
<td>One spouse reports for parents and children, self-reporting or proxy for other adults</td>
</tr>
<tr>
<td>Logical Implication</td>
<td>Medicaid of adults is attributed to their children</td>
<td>Medicaid attributed to AFDC/SSI recipients until 1996</td>
<td>Minimal</td>
<td>Similar to CPS</td>
<td>Minimal</td>
<td>Medicaid attributed to TANF recipients</td>
</tr>
<tr>
<td>Catchall question</td>
<td>Asked</td>
<td>Not asked</td>
<td>Asked</td>
<td>Asked</td>
<td>Asked</td>
<td>Not asked</td>
</tr>
<tr>
<td>Verify uninsured</td>
<td>Added in 2000</td>
<td>Added in 1997</td>
<td>Reasons why uninsured$^c$</td>
<td>Reasons why uninsured$^c$</td>
<td>Asked</td>
<td>Asked</td>
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<tr>
<td>Eligibility for employer insurance</td>
<td>Not asked in March supplement</td>
<td></td>
<td>Asked</td>
<td>Asked</td>
<td>Asked</td>
<td>Asked</td>
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<tr>
<td>Status before survey</td>
<td>Not asked</td>
<td></td>
<td>Asked</td>
<td>Asked</td>
<td>Asked</td>
<td>Asked</td>
</tr>
<tr>
<td><strong>Other Data</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Health care use</td>
<td>Not asked</td>
<td>2-week and 12-month recall</td>
<td>4-5 month recall</td>
<td>Selected interviews 12-month recall</td>
<td>12 month recall</td>
<td>12 month recall</td>
</tr>
<tr>
<td>Employment data</td>
<td>Extensive</td>
<td>Extensive</td>
<td>Extensive</td>
<td>Extensive</td>
<td>Extensive</td>
<td>Extensive</td>
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<tr>
<td>Data Availability</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

a. Each CPS panel is interviewed for four months and then interviewed in the same four calendar months a year later.
b. Panels alternate between larger and smaller sample sizes. Two panels can be combined for 1997 and all subsequent years.
c. Aid to Families with Dependent Children/Supplemental Security Income.
d. Lack of insurance is not explicitly verified, but the uninsured are asked for “reasons why uninsured.”
e. Employment status, hours, earnings, insurance eligibility for all adults.