Commentary—How to Improve Federal Health Data for Coverage, Access, and State-Specific Needs

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The health research and policy communities have made significant progress in recent years in improving the data and analysis needed by federal, state, and local officials to guide policymaking on the uninsured. If the United States provided universal coverage to all Americans and had implemented a uniform electronic medical record, we might not have to depend on survey data as much as we currently do to assess the extent and consequence of being uninsured. Health surveys can provide critical information on insurance coverage and access to care at the national, state, and community levels that policy makers need to monitor the performance of the health care system and to develop programs to respond to shortcomings like excessive cost growth, uneven quality, and inequitable access to coverage and care.

The principal federal agencies that produce these data are the United States Department of Commerce's Census Bureau, the Centers for Disease Control and Prevention's National Center for Health Statistics (NCHS), and the Agency for Healthcare Research and Quality (AHRQ). Recognizing the need to augment the availability of reliable and timely state and community health data produced by the federal agencies, national foundations over the last several decades have sought to fill identified gaps—both in the questions asked and the ability of these surveys to produce estimates at the state and substate level.

These data help national policy makers understand the variations across our nation and help state and community leaders develop programs to meet the needs of their citizens. For example, in 1993–1994, the Robert Wood Johnson Foundation (RWJF) funded the State Initiatives in Health Care Reform Program, which included both population and employer surveys in 10 states to assist those states in developing their plans to meet the needs of their uninsured populations. More recently, RWJF funded the Community

Tracking Study to provide information on 12 metropolitan communities. The National Survey of America's Families, which was co-funded by the Annie E. Casey Foundation, W. K. Kellogg Foundation, RWJF, the Henry J. Kaiser Family Foundation (KFF), and other philanthropies, gathered information on 13 diverse states that account for a large share of the nation's population. The Commonwealth Fund fielded multiple surveys on employer-based health insurance and KFF, along with Health Research and Educational Trust, continue to conduct an annual survey of employers.

With this background and attention to the changing funding priorities of national foundations, AcademyHealth initiated a review of current national surveys being used to guide coverage and access policy. The results of this assessment are provided in AcademyHealth's report, *Improving Federal Health Data for Coverage and Access Policy Development Needs*. The most notable example of the change in national foundation priorities is the decision by RWJF to no longer fund large, nationally representative surveys of households and employers. These surveys have in the past yielded some state- and community-based estimates. Given the decision to discontinue these major sources of data that policy makers at all levels had been using to supplement ongoing federal health surveys, it is now more critical than ever to strengthen federal health data to meet these important needs.

The national health reform deliberations in the early 1990s and policy makers' demands for more state-level data led to notable improvements by the federal agencies in focusing on states as relevant geographic areas for estimates, as well as improving the speed with which data was released. Other programs evolved during this same period and debate, fueled in part by greater understanding of national and state-level variations in insurance and access. When the federal government did not enact substantial health reforms in the early 1990s, state governments were left to focus on incremental policies as the only viable option for addressing the issue of the uninsured. The federal enactment of the Health Insurance Portability and Accountability Act and the State Children's Health Insurance Program provided some direction for further reform of insurance markets and for expanded coverage for children of moderate income families.

To prompt states to consider an even broader range of reforms, the federal government also provided states with funding to develop plans or enhance current programs to address the uninsured through the Health Resources and Services Administration's (HRSA) State Planning Grants program. Most states used at least a portion of their HRSA grant funds to conduct their own state-specific surveys, assessing both the extent of their uninsured

problem and providing data to inform policy choices about different approaches for expanding coverage and access. For 2006, the Bush administration did not request additional funding for this program and states will have exhausted their HRSA funding by 2007. Without supplemental foundation funding or HRSA funds to support state surveys, states will now have to use their own scarce resources to gather data or rely upon the existing federal health surveys.

Besides these policy concerns, health services researchers are concerned about their ability to gain timely access to federal health data. Researchers were frustrated by the length of time it took AHRQ (then the Agency for Health Care Policy and Research) to release National Medical Expenditure Survey public use tapes. Though AHRQ has since shortened the time lag, Medical Panel Expenditure Survey (MEPS) files become available 2 years after the year for which they are collected. While researchers may not always fully appreciate the time it takes to process, prepare, and “clean” the data for public use, it is time to revisit the critical trade-off between quality and completeness of the data file and its more timely release, given the policy community’s growing need to have closer to real-time data to monitor system performance and make critical policy decisions.

Based on the findings from its Federal Health Data Project, AcademyHealth believes that both more federal funding and a strategic refocusing of current surveys are needed. If limited funding increases remain a short-term reality, we urge the federal government to continue its efforts to streamline and refocus current data collection resources to generate both more timely data release and more state- and community-specific data.

RECOMMENDATIONS

While the information gathered by the federal surveys is vast, the present combination of the federal health databases for coverage, access, and state and local needs does not meet current policy making needs. Furthermore, while researchers can aid in meeting these policy making demands, they can only do so if the data are released in a timely manner. The recommendations presented in AcademyHealth’s summary report, *Improving Federal Health Data for Coverage and Access Policy Development Needs*, were derived from a general consensus of experts at a meeting for this project. These recommendations focus around four major themes: (1) scope and integration of current federal surveys; (2) specific modifications/additions in current federal surveys; (3)

increased investments in methodological research; and (4) increased integration and coordination among agencies.

Scope and Integration of Current Federal Surveys

First, it is important to coherently and succinctly portray all information collected by the current federal surveys. This process would entail formulating a “map” of all federal surveys pertaining to insurance coverage estimates, access to quality care, and state and local health data. One of the primary benefits of such a map is that it would help identify not only redundancies in the myriad national surveys, but also opportunities for specialization and targeted research studies. Most importantly, in the existing funding environment, the savings realized from eliminating the duplications could be used to increase survey sample size and produce more subnational and small-area estimates. Furthermore, the map could help identify the most important items required for certain decision-making criteria and potential items to add to existing surveys. We believe the federal government should be responsible for creating and maintaining such a resource.

Specific Modifications/Additions in Current Federal Surveys

Data must be released in a timely manner so that policy makers and researchers can use it for their respective purposes before they become outdated. The Census Bureau issues its Current Population Survey (CPS) in a timely manner—within 6 months of collection. The NCHS’s National Health Interview Survey (NHIS) and AHRQ’s MEPS have improved the time lag from collection of data to the release of public use files (used by researchers to make their own tabulations using income data, labor force data, and health data). NCHS now releases the NHIS within as little as 6 months of collection but it still takes AHRQ two years to release the MEPS public use files. The MEPS annual expenditures variables are more complicated to edit and prepare in person-year formats than CPS or NHIS variables. Nonetheless, the unique ability in MEPS to link health care cost growth with specific clinical events is central to current policy debates. Policy makers and researchers recommend that AHRQ continue to shorten the time between collection and release of the MEPS public use files.

Increasing the sample size for federal health surveys would enable states and communities to develop better estimates of their uninsured populations. The need for better state and local estimates could also be facilitated through

partnerships among federal agencies, the states, and foundations (e.g., using buy-in mechanisms such as the State and Local Area Integrated Telephone Survey or funding a “mini” version of the MEPS survey). Finally, the content of the surveys must be improved, especially with regard to income data and insurance coverage data. While it is important to collect information on who is not covered, it is just as imperative to understand the type or extent of coverage of those who have some form of health insurance. Information on the type of coverage and how this level of coverage translates into access to services and ultimately to improve health outcomes, is vital in addressing major health care issues facing the nation.

Increased Investments in Methodological Research

Underlying methodological issues can significantly affect research interpretations and policy decisions that are appropriately made and not made on the basis of reported data. Balancing certain trade-offs could lead to significant improvements in the current federal health databases associated with federal, state, and local decision making. For instance, we alluded to the lack of appreciation for the trade-off between quality of the data and the time lag in releasing the public use files. The March Current Population Survey Supplement, which is released within 6 months of data collection, has one round of questions. MEPS, on the other hand, asks two rounds of questions each year to the same respondents and produces far more information on health status, access, use, and health expenditures. Regular explanations to policy makers and the research community of the timeliness–quality–completeness choices that data producers actually face would be a great way to engage the policy and research communities in an ongoing conversation about priorities and evolving policy-making needs.

Another crucial trade-off is between survey sample size and survey length (i.e., the number of questions that are posed). Increasing the sample size may yield more subnational or small-area estimates; on the other hand, asking more questions about type of coverage used and more detailed income information would yield more accurate answers in determining eligibility levels or eventual quality of health outcomes. Which would help decision makers and researchers the most and under what circumstances?

Yet another example includes the importance of longitudinal versus cross-sectional surveillance methods; criteria for both monitoring and evaluation or testing of program impact over time should be addressed when considering survey design and content.

Increased Integration and Coordination among Agencies

Significant improvements have been made in coordination, especially between AHRQ and NCHS. Michael O'Grady, who served recently as the Assistant Secretary for Planning and Evaluation at the Department of Health and Human Services (HHS), led an internal HHS process to improve federal health data. The Census Bureau's CPS serves as the only prominent survey that produces annual state estimates for all states. Further coordination is required within HHS, as well as across all federal departments. In a limited funding environment, stronger and more effective coordination efforts across the federal government will be needed. We believe that the Office of Management and Budget, in conjunction with HHS and the United States Departments of Labor and Treasury, should lead interdepartmental coordination across the federal government.

COMMISSIONED PAPERS

AcademyHealth project was limited to an assessment of national surveys used to inform policy and programs related to health insurance coverage and access to care by various population groups. We commissioned papers to summarize the efforts of the federal government in improving federal health databases and to fully understand the gaps in current federal surveys with regard to state and local information and the means of addressing these gaps. The two commissioned papers included in this issue of *Health Services Research* discuss how to improve federal collection of health information associated with access, coverage, and state- and community-specific needs.

"Toward a More Reliable Federal Survey for Tracking Health Insurance Coverage and Access," by Genevieve Kenney, John Holahan, and Len Nichols, discusses critical gaps in current federal surveys for insurance coverage and access to care, and suggests possible options for addressing these gaps. Kenney, Holahan, and Nichols draw upon the considerable experience they gained through working on the Urban Institute's National Survey of America's Families to highlight gaps in the current federal surveys that foundation-funded surveys have in the past been used to address. After reviewing the strengths and weaknesses of each major federal survey, Kenney and colleagues discuss which surveys are best suited to be modified to attempt to reach an ideal health survey for coverage, access, and state-specific needs. Among other steps in improving federal surveys, the paper makes a strong case for needing more detailed information on the types of insurance coverage and sources of income

for better understanding the relation between public program eligibility, actual types of coverage, access to care, and health outcomes.

“Meeting the Need for State-Level Estimates of Health Insurance Coverage: Use of State and Federal Survey Data,” by Lynn A. Blewett and Michael Davern, outlines why most federal surveys fall short of providing accurate state and/or local estimates and why we need to continue collecting state and local health data. Lynn A. Blewett, founding director of the State Health Access Data Assistance Center, draws upon her extensive experience in working with states to collect and analyze data about coverage and access. After detailing the criteria necessary for more appropriate scope and quality of state and locality information, Blewett and Davern outline specific additions in the current federal surveys to meet these needs. The CPS, Behavioral Risk Factor Surveillance System (BRFSS), and the State and Local Area Integrated Telephone Survey (SLAITS) are closer to providing the required information than other federal household surveys, according to their analysis. The shortcomings in the current surveys range from sample size and sample framing to using what now appear to be outdated surveillance methods such as random digit dialing. Their paper then describes four approaches to redress the lack of state and local health information and explains how the most effective solution would require the federal government and states to develop strong and multi-faceted, long-term partnerships.

MOVING FORWARD—DEVELOPING AND IMPROVING PARTNERSHIPS

Process Review

The process used by AcademyHealth during the course of the project can be a model for the federal government to use in future assessments of federal databases for health and health care. As conveyed in the recommendations above, obtaining the input of critical users including policy makers and researchers can be valuable to the federal government in these assessments. The input of impartial health services researchers and analysts using the data, combined with the support from the federal government, is crucial to informing federal and state policymakers as they address our nation’s coverage and access issues. The key components of the process included: (1) establishing an advisory committee to define the scope and goals for the project; (2) commissioning papers to assess the current federal health databases and address the needed improvements for more informed decision making at both the federal and

state levels; and (3) convening an “expert meeting” of funders, producers, and users of coverage and access data. The commissioned papers provided the essential background information and structure for the expert meeting held on improving federal health databases. These discussions led to the recommendations highlighted earlier.

Implications for Federal Government, States, Foundations, and Researchers

The AcademyHealth report provided specific steps that the federal government, states, foundations, and health services researchers should take in partnership to improve and federal health databases used to assess coverage, access, and state and community-specific needs.

Federal health data are a public good and should be accordingly funded with public dollars. Federal agencies producing data associated with coverage and access need to work with states to provide information useful for state and local decision-making. Developing, designing, and assessing incentives such as buy-in mechanisms would be facilitated by surveys that produce state, local, and/or population-specific estimates. The foundations should assist states by funding survey add-ons and providing technical assistance on appropriate uses of federally supported surveys. The federal government should also work in partnership with foundations to achieve a better balance between surveillance and research. While national surveys provide a long-standing and well-regarded way to assess overall needs, it will be important to complement these surveys with targeted research to help address specific policy questions. The federal government should also take the lead in developing procedures that make geographic identifiers available to researchers, thereby enabling more accurate findings. Foundations can continue to play a critical role in improving the development and use of federal surveys by commissioning investigator initiated research on research methodologies and survey methods.

With the change in national foundation priorities, the need to improve federal health surveys is even more imperative. The two commissioned papers included in this issue provide a roadmap for the changes that are needed. With leadership from the federal government and support from states, national foundations, and research and analysis communities working in partnership, we can inform policy makers’ critical decisions for improving health care coverage and access for all Americans.