

M O N I T O R

HEALTH CARE IN THE UNITED STATES

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SYNOPSIS

SURVEYS HAVE PROVIDED magnificent information about the health of the American people, but they rarely contribute to our understanding of how medical services affect people's health. The authors explore the opportunity to harness the medical services system to provide information that clarifies the relationship between people's health and the services they receive. They also note the risk posed by managed care—that competition and cost-cutting may pit the health industry against access to and standardization of health services data—but see hope in recent legislation.

Which country spends close to a trillion dollars on health care and cannot evaluate the impact of this spending on the population? Answer: the United States. The Federal government commissions more household surveys and collects more statistical information per head of population than any other country in the world. While a great deal is known about the prevalence and incidence of disease, about risk factors, and about the levels of disability, income, educational attainment, and material consumption in the U.S. population, far less is known about the impact of health services. Even less is known about the

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RING

A Challenging Task

role of health services in ameliorating inequalities in health. But this may all change if the Health Insurance Portability and Accountability Act of 1996 (P.L. 104-191) is fully implemented. For the first time the U.S. government could be in a position to monitor access to and outcomes of health care for all its residents.

In this article we examine the limitations of surveys and the advantages of collecting data directly from health care providers and payers. Comparing developments in the United States with experiences abroad, we describe the opportunities to collect and amass useful data and the obstacles that challenge our efforts. In conclusion, we urge the Department of Health and Human Services to seize the moment and act decisively on the new law.

Reliance on Surveys

In any health care system, data collection requires the cooperation of all participants. In systems in which the government acts as the universal payer, such cooperation is accepted as an essential element of accountability for public expenditures. The multitude of organizations participating in the United States's market-led, private health care system have little leverage to ensure across-the-board cooperation. And until now, the Federal government has seemed reluctant to demand that all health care providers participate in a national system of data collection.

The type and amount of data about an individual that are collected and stored depend on whether and where he or she gets care and who pays for it. The health status and health care use of the medically uninsured is particularly difficult to track since there are no payers receiving encounter claims and thus no central collection of data. Although the United States spends the highest proportion of any nation of its Gross Domestic Product on health care (13.7% in 1994),¹ in 1994 an estimated 39 million people under age 65 (17.3% of the non-elderly population) had no health insurance, private or public.²

For those who do have insurance, the multiplicity of government and private health plans and movement among them constitutes an obstacle to collecting good data. Approximately 55% of the population is covered by private health care insurance.³ Medicare, the Federal program for the elderly and disabled, covers 36.3 million people (32.5 million ages 65 and over and 3.9 million disabled), or 12% of the population. Medicaid, the health insurance program for the poor, covers 33.4 million people, or 11.5% of the population. These numbers include 1.7% of the population who are eligible for both programs.³ Our ability to monitor within and across health



plans is also affected by high turnover—as people disenroll, or as employers and insurers switch plans and providers.^{4,5} The profusion of payers and their often short-lived link to individual users of care have made it difficult to amass useful medical services data. The hundreds of payers are under no obligation to share data, making it difficult to monitor the impact of health care interventions across the population. In the absence of organized and standardized data collection, it is nearly impossible to follow what happens to an individual over time. Given these limitations, epidemiologists and students of our health care system must rely on survey methodologies to obtain information.

Unfortunately, sample surveys have several limitations:

- They rely on samples to represent large segments of the population. National samples can not provide sufficient numbers to paint detailed pictures of care for small subgroups or sparsely populated areas.
- Because they rely on data collected from individuals, surveys are subject to non-response and recall bias.
- Many surveys do not track care over time and so do not provide biographical accounts of the care of individuals.
- Sample surveys are expensive.



Federal surveys to assess medical care. The U.S. government fields the National Hospital Discharge Survey, the Current Medicare Beneficiary Survey, the National Health Interview Survey, the National Health and Nutrition Examination Survey, and the Health Records Survey Program, a provider-based survey that does not sample individuals. Since 1957, the National Health Interview Survey has helped to inform and shape the clinical and epidemiological research agenda in the United States. But there are limited detailed data on health care use in this sample and it can not be linked to the National Hospital Discharge Survey, which is based on "discharges" rather than people.⁶ Nor are data from the National Health and Nutrition Examination Survey linked to data from the National Hospital Discharge Survey. Even the linkages currently being attempted under the Survey Integration project⁷ will provide incomplete analyses of utilization because the sample can never be large enough to provide detailed analysis at the small geographic

area level or within subgroups of the population. "NCHS Dataline" in this issue.)

Surveys to monitor public health interventions. The United States also relies on surveys to monitor and evaluate

its national public health interventions. For example, screening programs for the early detection and control of breast and cervical cancer established following the enactment of the Breast and Cervical Cancer Mortality Prevention Act of 1990 (Public Law 101-354) have been studied using surveys. Incident cases of breast cancer have to be estimated from the states participating in the Surveillance, Epidemiology and End Results (SEER) program. The SEER program tracks only a sample of U.S. women residents. In contrast to many European countries, the United States has no national cancer registration system, and no agency possesses overall responsibility for monitoring screening, treatment, and outcomes. Five years after implementation, the effectiveness of the Act cannot be evaluated for want of good information.

Fragmentation of funding, screening, and treatment makes tracking patients an impossible task. They move from one funder to another and from provider to provider. For example, when a woman is diagnosed with cancer under a public program, she may not be eligible for treatment from the same program. Because the government does not require providers to report on women screened or on treatments given, mammography rates must be estimated from the National Health Interview Survey (NHIS)⁸ and the Federally funded Behavioral Risk Factor Surveys (BRFS) undertaken at the state level.⁹ In 1994, the NHIS sampled 127,000 men and women, 0.049% of the total U.S. civilian noninstitutionalized population of almost 260 million.¹⁰ At the state level, the BRFS drew upon much smaller samples.

In contrast, the United Kingdom's national breast screening system requires all providers to report detailed pathology and treatment data on all women screened and works closely with the cancer registries.¹¹ Consequently, the U.K. has fairly accurate data on the incidence of cancer, the use of mammography, and the treatment and outcomes for all women eligible for screening. Public health officials can also review the effectiveness of the national program by area

of residence, age, gender, social class, and place of screening.

Vaccination. Unlike the United Kingdom, the United States has no national child health surveillance system; instead, it again relies on the small samples drawn from the NHIS to estimate immunization rates. About 67.5% of children 19 to 35 months of age were estimated to be up-to-date with immunizations in 1994.¹² This compares with a known immunization rate of 92% at age one year for all children in the United Kingdom,¹³ where National Health Service general practitioners report on all individuals to the Department of Health and receive bonus payments tied to the percentage of their patients whom they vaccinate completely.

The Logical Solution: National Uniform Standardized Datasets

National uniform standardized datasets and methods for collection and classification across different settings are key to the ability to track and monitor care across all payers and all providers. Such data could be amassed centrally and then become widely available to health care researchers, planners, and clinicians. The United Kingdom and Canada, for example, have adopted and use minimum uniform hospital discharge datasets, but in the United States they have had a faltering and checkered history.

Data Collected by Payers and Providers

Medicare, Medicaid, insurance carriers, health plans, and providers all collect similar encounter and claims data on inpatient and outpatient care, but there is little standardization. Until now, the Federal government has seen little reason to become directly involved and has left it to the commercial sector to agree on standards for data collection. The result is an alphabet soup of over 50 organizations developing standards.

Medicare. Medicare, with a relatively stable population of 36 million enrollees, has the largest uniform collection of claims data in the United States. Using a unique identifier for each enrollee, the system can track an individual's medical care use. Inpatient encounters are recorded on the UB50 form, and outpatient Medicare data on the HCFA 1500 form. However, a new problem is emerging: encounter data on 6% to 10% of Medicare beneficiaries are currently lost because these patients are enrolled in managed care plans that are reimbursed on a capitation basis and do not send

claims to the fiscal intermediary. Growing enrollment in managed care limits the usefulness of the data collected from Medicare fee-for-services enrollees as well. When managed care organizations located in cities recruit healthier enrollees, residual data from the fee-for-service population may over-represent rural areas and less well persons.¹⁴

Medicaid. Since 1965, when Congress enabled states to design their own Medicaid programs within Federal rules, the Department of Health and Human Services has been reluctant to impose a requirement of a uniform national dataset with a unique identifier. In any case, because Medicaid covers a relatively transient population of individuals who move in and out of eligibility and between payers, monitoring their health care would require the cooperation of all payers both public and private.

States and large health plans. Until now, in the absence of Federal government intervention, the drive to establish

standard uniform datasets has come from within large HMOs and from state initiatives. Health plans such as Kaiser Permanente appear to be moving toward a completely computerized electronic patient record. California, Wisconsin, and New York have developed minimum core dataset requirements and have mandatory reporting requirements for hospital discharges.¹⁵

Without organized and standardized data collection, it is nearly impossible to follow what happens to an individual over time.

Efforts to assess quality. To market managed care on the basis of quality, health plans are developing their own datasets, known as *report cards*. Report cards, such as the Health Plan Employer Data and Information Set (HEDIS), have replaced the laborious and expensive chart review previously carried out by professional review organizations. HEDIS is a standardized set of 60 performance measures in the areas of quality, access, patient satisfaction, membership, utilization, and finance intended to allow comparison of health plans.¹⁶

Report cards examine the process of care for only a few diseases and conditions. Data are aggregated to HMO level and providers don't use common standards and definitions. Neither the quality of the data nor the validity of the measures has been established. And finally, the report card does not provide a community population-based focus and so is able to provide only a partial and incomplete picture of enrollees rather than of the care of the whole population. In the words of a Prudential Health Plan manager, "Our interest lies in the performance of our health plans and not the community's health."

Population-based experiments. While health plans collect data about their enrollees only, states have tried to create data systems for the whole population. The John Hartford Foundation has funded six areas—the states of Washington, Iowa, Vermont, Ohio, and New York and one metropolitan area, Memphis, Tennessee—to create all-inclusive health information data systems, Community Health Management Information Systems,¹⁷ which will allow information sharing on the health and health care needs within a community or state. These data systems currently rely on voluntary participation by health plans and private payers.

Managed care—what claims reveal capitation will conceal. We think that data on patient care will become even more fragmented and elusive under managed care. Descriptions of utilization, referral patterns, and outcomes will be critical to understanding how managed care organizations control costs. But health care researchers will find it increasingly difficult to answer these research questions.

Nationally, some 48% of private insurance beneficiaries are currently in managed care programs, as are 10% of Medicare beneficiaries and 32% of Medicaid enrollees.¹⁸ The states of California, Oregon, and Florida account for 60% of all Medicare enrollment in managed care plans.¹⁹ In the next five years, Medicare and Medicaid populations in other states will move rapidly into capitated managed care plans as private health plans extend their markets and Federal and state government push recipients into managed care plans to control costs.

Under capitated payment mechanisms, providers no longer submit claims, and thus encounter data are lost. And as large managed care corporations buy up smaller ones or merge, it becomes harder to enforce data standardization within plans. Kaiser Permanente, for example, developed a uniform standardized dataset for use in its staff model practices. What will happen as it begins to subcontract with independent physician groups and providers? Many of these providers lack standardized methods for collecting data and the information technology to process it.

Data ownership problems will also confront these plans when information is gathered and held by clinicians who choose not to share it with the health plan. As for-profit care becomes the norm, it is unlikely that the required

investment in data collection and information technology support will be a priority. Alert to this problem, some students of managed care have suggested that capitated HMOs should continue to submit encounter-level data (claims) to Medicare. Medicare would pay the cost of collecting and submitting these data.¹⁴

Early Efforts to Mandate Uniform Datasets

With these developments scattered across the country, we conclude that in the new era of managed care, a uniform standardized core dataset has become an even more essential requirement. The United States has been struggling with the idea of a standardized dataset for years. In 1972, a technical subcommittee of the U.S. National Committee on Vital and Health Statistics (NCVHS) reached agreement on the first uniform hospital discharge dataset.²⁰ There followed four Federal demonstration projects in California, Maine, Pittsburgh, and Wisconsin, but despite a positive evaluation, the use of the minimum dataset was never made mandatory.²¹ Periodic reviews have improved the standards and the content of these datasets but were never accompanied by a



mandate to use them.²²

To gain consensus on the need to standardize definitions for a limited core set of health data on individuals, NCVHS was asked two years ago by the Department of Health and Human Services to facilitate a collaborative public and private process. Charged with specifying a dataset for mandated external reporting, the Committee contracted for a compendium of core data elements and through May 1996 has consulted over 2000 organizations on these elements. Committee members reviewed a set of draft recommendations in April 1996; final recommendations are still awaited.

Hope Springs Eternal—The Administrative Simplification Subtitle

A dramatic sea change may be about to take place. When Congress passed the Health Insurance Portability and Accountability Act of 1996, which allows employees to take their health plans with them when they change jobs, it also passed an important subtitle to the Medicare and Med-

icaid program under Titles XVIII and XIX of the Social Security Act. The Administrative Simplification Subtitle is intended "to improve the efficiency and effectiveness of the health care system by encouraging the development of a health information system through the establishment of standards and requirements for the electronic transmission of certain health information." The standards include the creation of a national patient index and a unique health identifier for each individual, employer, health plan, and health care provider. With a short time, only 18 months, to implement this law, success hinges on cooperation from the health care industry. Faced with the prospect of higher short-term costs, the health care industry may refuse.

The enormity of the task is daunting. Unlike the United Kingdom, the United States lacks a national policy-making committee to agree on a core dataset and the process to implement it.²³ And the spirit of competition rather than collaboration could impede progress. Thus, there is a new urgency for health care researchers, clinicians, planners, and foundations to mobilize and support NCVHS, which, under the new law is charged with offering technical support and advice to the Secretary of the Department of Health and Human Services. The Committee's task will include working with standard-setting organizations to identify, define, agree on, and then implement uniform standards and core datasets. At the same time, insurers and providers will have to review and revise their existing data infrastructures. Also, important and difficult issues relating to the privacy of individually identifiable health information will need to be addressed.

In 1992, the Institute of Medicine panel on the National Health Care Survey wrote, "The current national data systems...do not provide the information needed to allow researchers and policy makers to assess adequately the effect of changes in the financing, organization and delivery of health care, or the impact of socioeconomic trends, on appropriateness, quality, cost and outcomes of care."⁶ If the Administrative Simplification subtitle of P.L. 104-191 calls forth the intended effort, for the first time in its history, the United States will have the means to monitor both the health and health care of its entire population.

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