THE CAPITOL FORUMS
On Health & Medical Care

THE NUMBERS GAME: HOW DATA SHAPES HEALTH CARE PRIORITIES & FUNDING

Background information for the discussion at the

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THE NUMBERS GAME: HOW DATA SHAPES HEALTH CARE PRIORITIES AND FUNDING

THE ISSUE:

In a time of budget reductions and shrinking resources, and while the Federal government moves to place more significant health program design and funding decisions in the hands of the states, greater accountability will be placed on state and local programs to supply reliable and convincing data in order to show program effectiveness, outcomes and merit. Current health information systems, which lack coordination in data collection, analysis and dissemination, are not sufficient tools with which to identify and evaluate health care priorities and funding. **How is an organized and coordinated system of data collection, analysis and information dissemination to be established among public and private sector players in the state and national health care delivery system? What kind of entity should have the authority to oversee these data initiatives?**

DATA, DOLLARS & PRIORITIES

When Congressional Budget Office Director Robert Reischauer was responding to Congress members' questions last year regarding national health utilization and fiscal data, he was asked by one Congressman if the Budget Office's estimates were "in the ballpark" (Bilheimer and Reischauer, 1995). His response was, "Congressman, I believe we are in the town the ballpark is in," reflecting the problems involved in relying on available health data to make significant policy decisions. According to Bilheimer and Reischauer, it is near impossible to construct a comprehensive picture of the health care system with today's databases (Ibid.). And what is not spoken in his response is clear: many priorities, policies and programs in the health care system have been decided based on incomplete, unreliable and sometimes faulty data estimates and projections.

On both national and state levels, health data experts agree that standardization and coordination of data is imperative in order for legislators and public policy makers to make sound planning and funding decisions. All acknowledge that what is <u>not</u> needed is yet another weighty tome of statistics; in order for data to be an effective tool in making budgetary and programmatic decisions, the development of a comprehensive health information system is required through which data is collected, analyzed and reported in a meaningful manner. Currently, there are national and state efforts to design, develop and maintain such comprehensive health data systems. The challenge confronting states is to evaluate existing state data sources, identify system weaknesses and to come to a consensus as to the viability of establishing and maintaining a comprehensive health information system to direct health care priorities and funding.

BACKGROUND

There are critical weaknesses in the health system infrastructure which compromise effective health care policy formulation, program design and funding decisions. One significant weakness lies in national and state health data and information systems. The chronic problem with health data collection and data analysis is that it has been plagued by unreliability, inconsistency and incomparability, that is, the absence of standard units of comparison. Producers and consumers of health data comprise numerous agencies and organizations in the public and private sectors.

The primary cause for these problems in the past has been that the reasons for collecting the data differ from one data collecting entity to the other. For example, most health and medical data systems were developed for the following reasons: reporting requirements mandated by the entity providing financial support to the program (such as Health Care Financing Administration (HCFA) requirements for the Federal Medicare or Medicaid programs); for the providers' benefit (hospital discharge data), or for data required by licensing entities (state Departments of Health and Insurance; accreditation organizations). Because each organization has different reasons for collecting the data, these different data reporting mechanisms are not standardized; as a result, definitions and terms differ widely. On the state level, health and medical data is gathered by different sources for different reasons.

The problem is further complicated by the reality that health and medical data sharing has also been affected by "territoriality," so traditionally it has not been freely shared among the separate data collecting agencies.

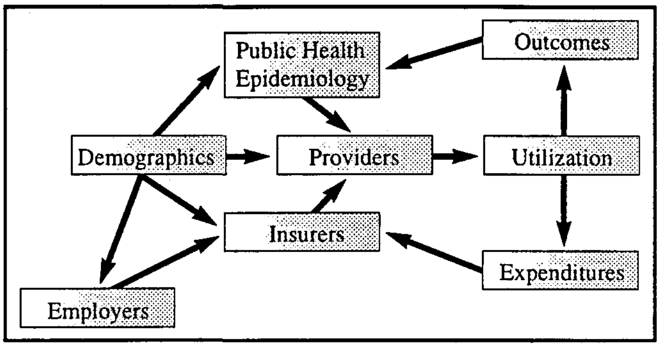
As the health care delivery system evolves, yet another factor has emerged to affect the health data infrastructure: managed care, with its emphasis on capping costs, has brought the issue of quality of care to the forefront. Consequently, there is great interest in developing performance measures in order to evaluate outcomes, along with collecting utilization and fiscal data. Each of these issues challenges us to understand the different kinds of data and how they are to be used by policy makers in order to make funding, planning and program decisions. As states become more significantly involved in planning and funding their health care delivery systems, much depends on their ability to demonstrate needs as well as positive outcomes and program effectiveness (Miller Jones, 1995). Data systems will play a key role in assessing and evaluating these health care priorities and funding.

WHAT IS HEALTH & MEDICAL INFORMATION?

"Quantitative data description and analysis provide the basic means for understanding the nature and health status of the population the health care delivery system serves and of the system's operations." (Jonas, 1995). Traditionally, health data has been collected and analyzed from three basic quantitative perspectives: (1) the demographic characteristics of the population being served (e.g., age, sex, socio-economic factors); (2) the health and sickness status of the population, where the ill-health status of the population is described by measures of mortality (death) and morbidity (sickness); and (3) utilization data as represented by who uses how many of what kinds of health services, when and where. When these three types of data are combined, such quantification describes how many of what kind of people are at risk, what kinds of diseases and ill health conditions they have, how these problems are distributed in the population, and who goes where for how many of what kinds of health services, delivered by which types of providers. The reporting, collection and analysis of fiscal data is used to dovetail with utilization and encounter data (data collected by providers and insurers about health care consumers), so that dollar amounts and health care expenditures can be ascertained.

The chart below, "Existing Data on Health Care Delivery & Financing," indicates the different types of health data in the current health care arena. The most reliable information available at the present time is in the areas of demographics and utilization. The weakest data elements are health care expenditures and outcome and performance measurement data, two factors upon which effective health care policy development is greatly dependent.

Existing Data on Health Care Delivery & Financing



Source: Nichols (1995)

As envisioned by health data experts, a comprehensive health information database in the 1990s must include the following elements to be an effective, decision-making tool: (1) health status data (birth, illness, disability, functional status and death; risk behaviors); (2) health resource data (supply; distribution and characteristics of the health work force and facilities and health plans); (3) financial data (costs, prices, payments, premiums and expenditures); (4) population data (demographic and socioeconomic characteristics of general population and enrolled populations); and (5) health outcomes and quality data (outcome measure on appropriateness of care and performance and accountability measures, such as access and patient satisfaction) (NAHDO, 1994). Within the operations of such a comprehensive database system, the interchange of information can be used to identify unmet service needs, calculate service projections and costs and to evaluate the effects and effectiveness of health programs.

NATIONAL & STATE OVERVIEW

National Health & Medical Information Sources

On a national level, health and medical information is collected and reported by various Federal agencies and organizations. Much of this data collection is mandated by law and is tied to the receipt of monies. For example, the U. S Bureau of the Census is required to take a census of the nation at least once every ten years. Since 1960, the National Center for Health Statistics (NCHS) has collected vital statistics (numbers of births, deaths, marriages and divorces) on a regular basis. NCHS also collects information and reports on health status, lifestyle and exposure to unhealthy influences, the onset of illness and disability and the use of health care. This information is used by policy makers in Congress and the Administration, by medical researchers and by others in the health community. Congress also uses utilization and fiscal data collected from the states by the Federal Health Care Financing Administration (HCFA) for its Medicare and Medicaid programs.

In the U.S., morbidity data are published on a regular basis by the National Center for Health Statistics and for reportable communicable diseases, the Centers for Disease Control and Prevention in Morbidity and Mortality Weekly Report. Within the National Center, the data sources include the Health and Nutrition Examination Survey, the Health Interview Survey, the Hospital Discharge Survey (hospital utilization data), the National Survey of Ambulatory Surgery, the National Nursing Home Survey, the National Home and Hospice Care Survey and the National Ambulatory Medical Care Survey. The NCHS surveys provide good annual information linking household demographics and utilization of health services (Nichols, 1995).

Concurrent with Federal government data collection activities, national associations like the American Hospital Association collect and annually report on both hospital utilization data and ambulatory service utilization data from the provider perspective.

❑ *National Data – Where are the Gaps?*

As Congressional Budget Office Director Robert Reischauer pointed out in his testimony on health care reform before Congress, health information databases currently available on the national level are incapable of providing a comprehensive and accurate picture of the health care delivery and financing system. What is known must be pieced together from several inadequate or dated surveys and sources, such as the Current Population Survey, the National Health Interview Survey and the Health Care Financing Administration. Historically, data collection activities tend to be overlapping, fragmented, lacking standardization and often duplicative (Jonas, 1995).

For example, the National Medical Expenditure Survey (NMES) of the Agency for Health Policy and Research is the nation's primary source for linking demographic information to health expenditures through employers, insurers and providers. However, NMES is conducted only once a decade, the last time in 1987. So the national data on the distribution of expenditures by demographic subgroup suffers from problems of timeliness. While the National Health Interview Survey, via the National Center for Health Statistics, samples the entire U.S. population, they cannot provide local data (from an individual city, town, county or state). Local data on how many and which type of hospital inpatient services consumers use is available in a minority of the states. Although HCFA has state-specific data generated from its Medicare program, it covers only people over the age of 65. Local data on health activities that occur outside of the hospital is scarce for all age groups, since no state has mandated that physicians or insurance companies submit copies of bills for services rendered outside of the hospitals.

☐ *National Projects towards Standardization of Health Information*

In an effort to remedy chronic health and medical data problems of standardization and fragmentation, several large-scale data projects are underway on the national level. Every current health data effort on national and state levels focuses not on producing more data, but on the development of core data sets and the sharing of accurate and reliable data. Beginning in 1995, the National Committee on Vital and Health Statistics and the Department of Health and Human Services have started a process to identify a set of core health data elements on persons and encounters or events. The Committee is seeking to facilitate consensus development and to build the concepts of multiple use and long-term evolution of core data elements into general thinking and practice among public and private health information, creating uniform, shared data standards, including definitions and medical forms (Miller Jones, 1995).

National efforts towards standardization of data also involve the Health Care Financing Administration (HCFA), which is engaged in defining a core data set for states and managed care plans and is in consultation with the National Committee on Vital and Health Statistics. HCFA is working with the Medicaid-Medicare Common Data Initiative Steering Committee (McData) for coordinating managed care data issues for the Medicare and Medicaid programs. Special attention is to be paid to improving data in the areas of access and utilization monitoring, quality assurance and improvement and capitation rate setting.

Current and potential uses for core data sets as envisioned by the National Committee on Vital and Health Statistics include payment and cost-related uses, planning and budgetary uses, performance measurement, clinical case management, consumer satisfaction reports, and public health status analyses. In her September 1995 letter to colleagues soliciting input regarding development of core data sets, the Committee Chair points out that unless more ways can be found to create greater data agreement among suppliers and users of health data in both fee-for-service and managed care environments, the innovative efforts such as the development of "report cards" for use by consumers and purchasers, and quality improvement efforts will be "thwarted" (Miller Jones, 1995).

The American National Standards Institute's (ANSI) Health Information Standards Planning Panel (HISPP) is another key player in facilitating national coordination needed to develop standardization in the collection and transmission of encounter-level health data.

In the managed care arena, the National Committee for Quality Assurance (NCQA) has been conducting accreditation reviews of managed care entities since 1991. NCQA released a set of performance measures for health plans in 1993 - the Health Plan Employer Data and Information Set (HEDIS 3.0 in 1996). HEDIS, which allows health plans to standardize how they calculate and report performance, will eventually enable all plans to measure performance in the same way. Prior to the HEDIS initiative, the evaluation of data across health plans was problematic, as not all plans collect or aggregate data in the same way (See, June 14, 1995 Capitol Forums Issue Brief, "Quality Assurance").

The National Association of Health Data Organizations (NADHO) coordinates the activities of some 200 health data organizations and groups throughout the country. Founded in 1986, Association members include representatives form state health data organizations (38 states); Federal health agencies; employers; insurers; state hospital associations and individuals with a commitment to: (1) improve the accuracy and comparability of health data and (2) promote the use and dissemination of health data to manage current and future health problems. Through its efforts, NADHO supports the development of public domain (non-client identifiable) health data organizations and promotes uniformity and standardization of health data collection and dissemination among public, private and voluntary data collectors and users.

Other States

☐ *Public – Private Partnerships*

With looming Federal cutbacks, how might state governments utilize partnership opportunities with the private sector organizations? The National Committee on Vital & Health Statistics and the National Center for Health Statistics view as a primary issue to explore the types of partnerships that may be formed between government and private sector organizations to develop information systems and large-scale data networks to share data more widely and efficiently (Id). On national and regional levels, public-private partnerships are emerging which may take forms ranging from consulting and planning to collaboration in the development of new information systems. The partnerships enhance the usefulness of public domain data databases and leverage available resources and expertise (NAHDO, 1994). One example of a partnership project to help states strengthen their health data systems is the Robert Wood Johnson Foundation's State Health Policy (InfoSHP) program, established in 1992. The program looks at the effectiveness of state data, taking into consideration both the technical quality of data systems and strategic features.

Another example of public-private partnerships is the recent large-scale national effort has emerged from the Agency for Health Care Policy and Research (AHCPR) which is developing a Healthcare Cost and Utilization Project (HCUP-3) for the years 1988-1994.. The HCUP-3 project aims to build a federal-state-industry partnership in health care data that will become a national resource for evaluating health care delivery and system reform.

The John A. Hartford Foundation's Community Health Management Information System (CHMIS) initiative awards grants to states and coalitions comprised of employers, providers, payers and public agencies in order to facilitate financial transactions and communications through computer-based technology. New York state is one state developing a CHMIS system (described below).

Regarding standardization and coordination of health data to facilitate effective performance and outcome measures, the Foundation of Accountability has also been established on the national front. The Foundation is a group of public (Health Care Financing Administration; Department of Defense), private (AT&T; UPS) purchasers of health care, business coalitions, consumer groups and standard setting organizations (such as the National Committee on Quality Assurance and the Joint Commission of Accreditation of Health Organizations (JCAHO)) and experts in the field of performance measurement. Its mission is to develop a consensus among consumers and purchasers about how to present information to consumers needed to make informed decisions about the value and quality of health care. Data research is on developing standardized, patient-oriented quality measures.

☐ *Health Information Initiatives*

According to the National Association of Health Data Organizations, the ways in which the states collect and analyze health data varies widely. State leaders are aware that enormous amounts of data are being collected all the time, and far more effort is required to collect the right data in a systematic way, put it in useful form and make it available where its use can produce benefits. The issue of oversight authority in the collection and dissemination of health data is addressed differently across the country. For example, in the states of California, Maine and Massachusetts, data collecting functions reside in the state's health planning agency. In other states, an independent commission is responsible for data collection and dissemination, as in Florida and Illinois. Other models utilize a joint public-private agency or commission comprised of representatives from all segments of the health care industry. The National Association of Health Data Organizations reports that by 1994, 38 states (including New Jersey) had mandated that collection, analysis, and distribution of data on hospital use, charge or cost of care, effectiveness and performance, maintaining and state health data databases.

In 1993 the Minnesota State Legislature created the Minnesota Health Data Institute, a nonprofit, public-private organization with the overall goal of improving the quality of health care services in Minnesota. Through the integration of data systems, standardization and uniformity, the Institute aims to build upon existing data sources and quality measurement efforts and to improve the availability of reliable health care data. In its first published project (1995), the Institute reported findings from a statewide survey comparing 46 health plans, including private health insurance plans, Medicare and state programs. The health plans are evaluated in areas such as consumer satisfaction with plans, medical care, pediatric care and premium costs.

In the state of Illinois, the Illinois Hospital and HealthSystems Association (IHHA) is involved in various types of public-private partnerships regarding health care information collection, analysis and dissemination. In an ongoing collaborative effort with the Illinois Department of Public Health, IHHA has developed Community Health Information System reports, such as mortality reports trended over time and reports comparing specific communities within the state. The Illinois EDI Task Force, convened by IHHA in early 1995, is comprised of health care insurers, state and federal agencies and departments, employers, business coalitions and representatives from other health organizations. Its goal is to provide a forum for organizing information in Illinois to develop and provide recommendations on agreed-upon electronic standards for the transmission of health care information (IHHA, 1995). One other data initiative, IHHA's COMPdata (Comprehensive, Comparative Healthcare Information), is a database system that is a source for comparative hospital utilization, physician, financial and demographic information. Reports generated via COMPdata range from hospital utilization data to physician data by hospital and resource utilization data.

The Community Health Information Systems (CHMIS) (contracted by the John A. Hartford Foundation) collect and disseminate health care related data and analyses. CHMIS is a cooperative arrangement for utilizing information that is often generated and stored in many separate locations and is created by the combined efforts of purchasers, providers, payers, consumers and governments. The New York State Department of Health is involved in developing a CHMIS project and is building a repository of encounter data, claims, clinical data, plan provisions and enrollment files to evaluate certain outcomes such as eligibility confirmation, practice profiles, utilization patterns, financial reports and community health status.

New Jersey

☐ *Health & Medical Data Sources*

As discussed above, each state collects health and medical data for various reasons: mandates for participation in Federal health programs (Medicare, Medicaid, Veteran's Affairs); state-mandated reporting requirements (the reporting of public health information such as communicable diseases, immunization, and the cancer registry); and state-regulated licensing and certification requirements (hospitals, physicians, nursing facilities, etc.). As with other states, in New Jersey state-level data databases exist for vital statistics, licensure, Medicaid, environmental health, the cost and use of health services, facilities and programs, diseases and injury registries, mental health and substance abuse, as well as data on specific characteristics of the state's population. The various health data sources and data databases in the state are located among governmental departments and divisions: the Department of Health (encounter data; vital statistics; patient, provider and facility data); the Department of Insurance (medical insurance claims); the Department of Labor (census statistics and socio-economic data); the Division of Health and Medical Assistance (Medicaid) in the Department of Human Services (Medicaid program data for recipients and providers), in addition to the various county and local health boards. As with other states throughout the country, data is also collected and utilized by the various private insurance companies and corporate employers, which gather medical and health data on employees, both as employers and purchasers of health care.

☐ *New Initiatives in New Jersey*

New Jersey's health information initiatives involve the process of evaluating its existing databases and assessing the most effective way data collection and interactivity among these and other electronic databases can be accomplished. For example, the Department of Health's birth certificate registration database is currently evolving from paper reporting to electronic data capturing, by which hospitals can directly register births with the Department through electronic on-line reporting. Such a system enhances the timeliness and reliability of birth data, facilitating efforts when interventions for certain health conditions (e.g., birth defects) may be appropriate.

The Department of Health is also working on the best approaches to take for designing data collection and analysis in light of the evolving health care environment in the state. As a result of its role as regulator (hospital rate-setting and DRGs), the Department's data reporting requirements historically were focused on the collection of facilities data, reported by hospitals, clinics, nursing homes and other health care facilities. With rate-setting deregulation and the emergence of managed care systems offering the delivery of health care services "under one roof," facility-based data is no longer a sufficient tool for health policy and planning. As a result, the Department's health data initiatives are focusing on designing data databases that are delivery system based (as with the managed health care system), rather than facility-based.

In its proposed rules at N.J.A.C. 8:38, "Health Maintenance Organizations," the Department is authorizing the development of a performance and outcome measurement system for monitoring the quality of care provided to Health Maintenance Organization (HMO) members. The formation of a Healthcare Data Committee (to be comprised of providers, consumers, HMO representatives and departmental personnel [serving as ex-officio members]) to assist the Department in the development of its quality of care measurement system, is also described in the proposed rules.

In the area of electronic data interchange, current legislation places $2 million in the Department of Health to develop a Healthcare Information Networks and Technologies (HINT) system, an electronic network using standardized medical claims forms and electronic interchange of data in an effort to reduce the administrative costs of health care. Several bills addressing various aspects of HINT, including fraud issues and the formatting of the claims forms, will be introduced in the Legislature by February 1996.

HEALTH INFORMATION & CONFIDENTIALITY

As computer technologies advance and the demand for accurate and reliable data sources for health and medical data becomes more pronounced to facilitate health program, planning and funding activities, the social implications of comprehensive medical databases emerge. Such databases are being developed and maintained by institutions like hospital networks, managed care organizations, drug companies and commercial health information companies that market software to capture medical records information directly from public and private agencies. Confidentiality experts contend that the information collected in such medical databases has the potential to be misused to deny employment, entitlement or opportunities to individuals or groups identified in the database.

The Institute of Medicine's Committee on Regional Health Data Networks, in its 1994 report on health data in the information age, addresses use, disclosure and privacy issues raised by the proliferation of health and medical data databases. The report recommends that Congress enact pre-emptive legislation creating a uniform privacy standard and defining a Code of Fair Health Information Practices for health data organizations and medical information networks, specifying sanctions for disclosing patient information that is confidential. In response to such concerns, Congress is currently considering the Medical Records Confidentiality Act of 1995 (U.S. Senate Bill S. 1360), which aims to ensure the privacy concerning release of medical records and information.

CONCLUSION

Effective health care policy making and funding decisions will require that information be accessible on issues cutting across public and private sectors, as well as on issues related to diverse programs and services (Feldman et al, 1995). Health and medical data experts have the knowledge and experience to design "state-of-the-art," comprehensive health information data databases in order to generate reports, health service projections and cost estimates to direct health care priorities and funding. However, establishing and maintaining such health information network requires a long-term commitment of resources and funding on the part of the individual state. As New Jersey and other states proceed with their health information initiatives, the challenge will be to maintain ongoing support of these projects, which play a key role in evaluating health care priorities and funding.

QUESTIONS FOR DISCUSSION

☐ On national and state levels, health data experts are in agreement that the establishment of a coordinated and comprehensive health information database is a key requirement for health policy makers and planners. What is New Jersey's long-term commitment to establishing such a comprehensive system of health and medical information to facilitate policy, planning and budgetary decisions?

☐ Two major state data reform initiatives — the Colorado Health Data Institute and the North Carolina Data Institute — recently terminated when enabling statutes sunsetted as a result of political and interest group pressure. How can any similar initiatives in New Jersey withstand the inevitable shifts in political backing over the long haul?

☐ State health data organizations throughout the country, including New Jersey, are working to create health and medical databases that are standardized and able to share information with many public and private entities. What is the degree of public oversight regarding these initiatives? Who — public sector? private sector? both? — manages and "owns" these data?

☐ "State culture is not replicable from state to state." This was the response given by Mark Epstein, Executive Director of the National Association of Health Data Organizations, when asked in a recent telephone interview which states had the most interesting health data initiatives underway. As illustrated in this Issue Brief, several states (including Illinois, Washington and Minnesota) have established data initiatives; however, based on various complex factors, each state has its own health and medical care delivery infrastructure and socio-economic variables with which to consider. What type of data initiative is viable for New Jersey? What is the best way for the state to develop an integrated health information system?

☐ On a national level, U. S. Senate Bill S-1360 has been introduced regarding confidentiality and privacy of personal information and medical records stored in large, informational data databases. Several health data experts are calling on support for these bill, as confidentiality laws vary from state to state. Where does New Jersey stand on the issue of privacy of medical records? Are New Jersey's current confidentiality laws regarding medical records sufficient in the face of the information age advancement of electronic record-keeping and data transmission?

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