The New Jersey Policy Forums
on Health and Medical Care

MUST DATA BE SO DEADLY: HOW SHOULD INFORMATION INFORM HEALTH POLICY DECISION-MAKING?

Background information
for

THE NEW JERSEY POLICY FORUM
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MUST DATA BE SO DEADLY:
How should information inform health policy decision-making?

ISSUE: What is the responsibility of state government among other health care players in the arena of health information and the dynamic environment of deregulation? Can New Jersey serve as a model state in developing a coordinated health information system that produces usable and appropriate information to guide state health policy decision-making efforts to collect, collate and communicate data and information for all users?

INTRODUCTION

In the popular movie, Contact, a momentous occasion of universal proportions is taking place: the people of planet Earth are receiving messages from somewhere else deep in the galaxy. The audio signals are "translated" into thousands of pages of instructions, equations and numbers. Yet, the researchers, scientists and political leaders cannot read the message until they discover the "primer" to make all of the information being transmitted comprehensible to them. Without the primer — until the "code" can be broken — decision makers cannot answer even the most fundamental questions about the nature of those sending the messages: are they friends or foes; teachers or destroyers?

The same questions — although much less "sexy" — surround the issue of the dissemination and the applicability of usable health data, i.e, turning health statistics into usable information for national and state health policymakers. As "deadly" dull as health statistics appear, they comprise one of the most critical dimensions of health care because their right or wrong interpretation drives health care policy and planning, program design, funding decisions and development. How can these volumes and data bases of health statistics — considered problematic to most except for a few, stalwart researchers — be translated to policy-relevant information to answer the questions raised by policymakers and to enhance the funding, accessibility and quality of our health care system?

Current research on health information systems and their development by states indicates that in most cases the *"data is there"; the challenge is to extract it and have it be* responsive to policymakers who are under time constraints and deadlines for making decisions. This challenge is complicated by several issues: health data mechanisms are not replicable from state to state, and the ways in which the states collect and analyze health data varies widely and is specific to each individual state's health care infrastructure. There are also differing health care data audiences that cut across public and private sectors — purchasers, consumers, providers, policymakers — each with a different interest and requirement for a specific type of data. What are some effective forms and formats for health information to be made meaningful to state policymakers?

In Appendix A., Table 1, (page 7) "Source of Insurance Coverage by State, 1994", exemplifies one type of formatting of "policy relevant" information that is available on the New York State Department of Health's on-line database accessible through the Internet. Several characteristics emerge when analyzing how the data is presented on the one-page table: states are listed in order of those with the highest level of uninsured to those with the lowest (rather than in alphabetical order); the breakdown of each category of insurance coverage — public, private and uninsured — is shown in real numbers and percentages of the population; and national averages and percentages are given. Both inter-state and national comparisons can be made, as well as regional comparisons. The source is clearly given, so that analysts are made aware of any limitations inherent in the data source; finally, a policymaker can access another site on the database for information on a specific category, for example, how does public insurance coverage break out in terms of Medicare and/or Medicaid coverage for a specific state's population.

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NATIONAL DATA INITIATIVES - AN UPDATE

On both national and state levels, initiatives and projects continue to work towards the creation of comprehensive and coordinated health information systems to be used as effective decision-making tools. However, historically, there have been and continue to be structural obstacles in reaching the goal of establishing such a comprehensive system that can provide reliable information about health status; health resources (supply, work force distribution and facilities planning); financing (costs, prices, premiums and expenditures); population data; and health outcomes and quality data. (Reference is made to Capitol Forum Issue Brief, "The Numbers Game: How Data Shapes Health Care Priorities and Funding," January 31, 1996.)

These obstacles include the absence of standard units of comparison, non-standardized reporting mechanisms, and the reality that health and medical data is gathered by different sources for different reasons and for different audiences. Historically, national and state agencies have been responsible for collecting data; however, "mechanisms used to convey results were fragmented and failed to integrate the multiple databases maintained by multiple government entities" (Mendelson & Salinsky, 1997). Accountability is the buzzword in our current deregulated health care environment, and initiatives to coordinate the collection of utilization, fiscal and performance health data are critical stages in the process towards assessing accountability.

In a recent piece on the role of states in accountability for quality, National Academy of State Health Policy Executive Director, Trish Riley offers a perspective on the public sector's role in such activities. Pointing out that the "science of building good systems of accountability is relatively slow, compared with the politics of quality, which is fast and volatile," she calls on legislators to strike a balance between the need for a reliable science of accountability and the political realities they confront involving consumers' worries about health care quality and services (Riley, 1997). What types of "checks and balances" can be put in place so as to avoid the troublesome trend of "legislating" quality in health care?

THE PLAYERS

The players in these health data projects and initiatives include the National Committee on Vital and Health Statistics, the Health and Human Services Data Council, the Agency for Health Care Policy and Research, the National Association of Health Data Organizations, the Center for Health Research and Communications, the National Committee for Quality Assurance, the Foundation for Accountability and the Joint Commission on Accreditation of Healthcare Organizations. Reference is made to Appendix B. (page 8) for updated detailed information on their activities.

National health data initiatives can be grouped into three basic categories:

(1) standardization and coordination of health data;
(2) development and application of performance measurement and outcomes in quality research; and,
(3) research and evaluation efforts reporting on health status of people and programs.

With the evolution of the health care system into a deregulated environment and the stronger presence of managed health care, the importance of outcome measures to assess quality and appropriateness of care, access and patient satisfaction has come to the forefront. Purchasers of health care — in both public and private arenas — are focusing on such tools as "report cards," health plan evaluations and consumer satisfaction surveys to monitor effectiveness and performance.

Throughout the country, various private groups and concerns — in the absence of government's lead in establishing quality measures and producing report cards for consumers and payers — are developing their own projects and initiatives to guide consumers and purchasers regarding the costs and quality of health care. The production and dissemination of accurate and reliable data is riddled with complex problems, and the development of sound quality measures is still in its infancy. What is the role of government to "protect the public good" from faulty or inaccurate health information which may be generated by these entities?

NATIONAL INITIATIVES ON HEALTH INFORMATION AND POLICY

There are several projects and initiatives on a national level which are addressing the issue of data integration and the dissemination of information in an usable form to respond to questions asked by policymakers. In his books on the presentation and visual display of information, the author Edward Tufte underscores the importance of the ways in which information is presented in order for it to be meaningful to users. For columns of numbers, like musical notes, can lose their meaning (in Tufte's words, they often become "chartjunk"), if careful planning and critical analysis are missing from the equation of presenting the information.

Registry of State Data Integration Efforts

The U.S. Department of Health and Human Services (through the Lewin Group) has developed a Registry of State Data Integration Efforts that focuses on state data policy activities and key state contact persons. Data integration is defined in broad terms to include projects that range from community profiling systems that draw data from different sources to databases that collect information across providers, such as hospital discharge databases. The Registry, which monitors activities across the 50 states, indicates that data integration efforts within states break out into three distinct categories:

1. Policy-oriented efforts - which are focused on informing policymakers and other decision makers and include such activities as: creating decision support; the coordination of data warehouses (bringing together data from different sources); and retrospective linkages, such as Washington's "First Steps" database, which links Medicaid, birth certificate, substance abuse and child abuse records;

2. Service-delivery-oriented efforts - which are focused on supporting and increasing the efficiency of health care delivery; and

3. Activities to support data integration, such as standards development and automation of data information systems.

Reference is made to Appendix B. for detailed information about these national health information initiatives.

STATE INITIATIVES — GROUND ZERO

As devolution continues, the state-level environment is the dynamic setting for innovation in health information activities and projects. In responding to their respective state's health information needs, every state across the country is engaged in some type of data integration and health information activity in order to improve the effectiveness and efficiency of the health care system. While some states have made the decision to pursue comprehensive information initiatives, others are taking incremental approaches to develop systems along one dimension of health care, e.g. public health or immunization data bases.

From the data warehousing projects in the states of Massachusetts, New Hampshire, Indiana and Colorado, to the Community Health Information Partnership in the state of Washington, such initiatives cover a broad range of data coordination, integration and dissemination activities.

A recent study conducted by The Lewin Group looked at the issues surrounding health information systems and the role of state government. Two main achievements of innovative state systems were reported: the systems reduced certain administrative and clinical costs and they improved the availability of health care data. Such achievements would appear to be attractive goals to all players in the health care arena. Are they enough, however, to encourage the type of long-term strategic planning and funding commitments necessary to develop and maintain such health information systems?

Additionally, study findings indicated that the governance of such projects varied greatly from state to state. Models ranged from single agency governance, to cross-agency collaborations, and from state legislature governance (usually a commission with the authority of the state legislature) to public/private partnerships. While some health data initiatives created by state legislatures have been successful, others (such as those in Vermont and Montana) have not succeeded, partially as a result of being more vulnerable to the political climate of the time (Ibid).

Other factors influencing state health information projects and the role of government in their development include questions of management; funding; confidentiality and security, and decisions about the use of existing resources. In terms of management, the states of Utah and Minnesota both came to the determination that management of ongoing data initiatives would best be done by transitioning to the private sector. The Lewin study found that in the area of funding, a mix of public and private funding supported innovative health data initiatives among the states. Most states, however, appeared to prefer to develop a public-private partnership to leverage state dollars in order to secure continued support for their health information efforts (Id). Regarding confidentiality of personal records and security of data systems, it is critical that states set levels of access to different types of data to ensure patient confidentiality and the security of health information data systems.

The following summaries highlight some individual state health data and information activities:

Minnesota

In the area of measuring and improving the cost-effectiveness of health care, the Minnesota Health Data Institute (formally created by the Minnesota Legislature in 1993; operational in 1994) has as its mission to support the information needs of consumers, purchasers, health plans and policymakers. The Institute, or MHDI, is a not-for-profit contractual partnership between the state's Commission of Health and a 20-member board of public and private organizations. Public sector representation also includes the Department of Employee Relations and the Department of Human Services. Funding support comes primarily from a variety of private sources (70 percent), while state government provides the remaining 30 percent.

MHDI's past and future projects include a 1995 and (planned 1997) Health Plan Report; which may be produced into two separate performance reports: one for consumers and one for purchasers; and a "Condition-Specific Measurement Report", which would evaluate six major conditions — including asthma, breast cancer, depression, diabetes, ischemic heart disease and pregnancy/childbirth. A 1996 summary report was submitted to policymakers; the report looked at categories of plans (for example, HMOs vs. fee-for-service; public vs. private plans) to highlight how different types of plans performed against each other. The Buyers' Health Care Action Group (BHCAG), a group of 23 large, self-insured employers (including the Minnesota Department of Employee Relations), based in Minneapolis-St. Paul is one audience for the performance information disseminated by MHDI.

Washington

The Washington State Community Health Information Partnership, a project of the nonprofit, public-private partnership — the Foundation for Health Care Quality — bridges the concerns of medicine, insurance, managed care, government agencies, employers and consumers. Its activities are designed to improve health information resources in the state through developing electronic network development, quality assessment and consumer affairs.

Colorado, Kansas and Nebraska

The states of Colorado, Kansas and Nebraska are involved in a multi-state effort (with multiple funding partners) to use the technology of telemedicine to reach rural and underserved areas of their states. Telemedicine networks communicate medical images and information for consultation, diagnosis and education. This multi-state telemedicine network is designed to connect ten rural and frontier facilities; funding is being provided by the Health Care Financing Administration (HCFA), member dues, grants and state government (Mendelson & Salinsky, 1997).

California

The improvement of health information systems can result in the building of state capacity as a purchaser of health care. The state of California plans to analyze Medicaid expenditures and utilization in new ways once HCFA approves proposed revisions to its Medicaid management information system. HCFA's revisions will integrate and produce basic clinical and financial data about the Medicaid program. California's initiative with its Medi-Cal program would create a management information system that contains all fee-for-service and managed care Medicaid claims and encounters (The Lewin Group, 1997). Analysis of such coordinated data would assist in setting rates and identifying potential areas of clinical problems.

New York

An example from New York State evolved partially from its involvement as one of the InfoSHP grantees. New York's Health Expenditures Reporting System (HERS) program aims to make policy-relevant information readily available to policymakers. Representatives from the public and private sector were brought together to design the system, which tracks the flow of funds from payers to providers and services, accounting for total health care spending in New York State. The HERS system was designed to present information in a way which would be most relevant to and usable by the state's health policymakers. (See Appendix A., Table 1, as an example of a "policy-relevant" presentation of "Sources of Insurance Coverage by State, 1994".)

Pennsylvania

The state of Pennsylvania's Healthcare Cost Containment Council's activities exemplify its decision to release data in "report card" format to consumers. At present, many states are reluctant to distribute this data, while others are directly involved in disseminating it (Id). The Council's database includes information from over two million hospital discharges, payment data from payers, outcomes data collected form hospitals, and small-area analysis data. Reports generated from the Council and available to consumers have included such topics as a guide for consumers to coronary artery bypass graft surgery and a report on hospital effectiveness.

BUT WILL IT PLAY IN NEW JERSEY?

Just as in each and every other state, New Jersey's activities surrounding health data are driven by working with the systems already in place and developing new systems to meet the unique health care needs of its citizens in a climate of fiscal constraint . New Jersey's various health data and information projects are continuing in many arenas: data coordination, public health services and performance outcomes. New Jersey state agencies — Health and Senior Services, Human Services, Insurance, Labor, etc., — continue to work on the best approaches to take for designing data collection and analysis in light of the evolving health care environment.

With multistate employers, health plans and consolidation of delivery systems, is there need and interest for regional cooperative ventures? Do we need discrete tracking of New Jersey's citizens' utilization of health care in our border states or should health status data be organized in units even smaller than counties, ie., by legislative district?

As part of a public health data initiative, New Jersey is one of 14 states selected by the Federal Centers for Disease Control (CDC) to participate in the LINCS system, which stands for Local Information Network Communications system. (Nationally the system is known as the Information Network for Public Health Officials, or INPHO). Under the LINCS system, each of the state's 21 counties will have a LINCS site, along with the public health departments in the cities of Newark, Jersey City and Paterson. Public health officials at LINCS sites will have access to a range of information from state and national databases and will be able to communicate with each other when a health emergency arises.

LINCS is also a communications system which will provide population-based data and information statewide. The system will include prevention-related information on such subjects as childhood immunization, cancer and reports of disease outbreaks. For example, one of the first databases to become a part of LINCS is the state's Statewide Immunization Information System (SIIS). Start-up costs for the LINCS project are being supported by approximately $1 million in Federal CDC funds (*The Star-Ledger*, July 19, 1997.)

In November 1994, the New Jersey legislature received the final report of a commissioned study on Electronic Network Solutions for Rising Healthcare Costs. This document, now known as the Healthcare Information and Network Technologies report , or the HINT report, identifies a goal to reduce the administrative costs of healthcare through an electronic network using standardized medical claims and electronic interchange of data. This type of system is similar to electronic data interchange systems in other states whose goal is to integrate health data. Beginning in fiscal 1996, $2 million per year has been designated by the legislature to the Department of Health and Senior Services to pursue the goals of the HINT report.

The legislatively funded HINT grants are currently supporting the following projects:

1. **Charity Care On-Line Management and Eligibility Verification Systems (CCOMEVS).** The CCOMEVS project, mandated by the 1997 Charity Care legislation, is designed to create a management information network among hospitals to assist in the identification and data collection process for patients eligible for charity care. This project will allow hospitals to rapidly share charity care information among each other and the Department of Health and Senior Services. This will reduce their administrative costs, provide more timely information to all involved with charity care, and allow the Department of Health and Senior Services to analyze and audit charity care data in a timely fashion.

2. **MIDS Replacement**
The Department of Health and Senior Services currently collects and processes data on the 1.1 million inpatient discharges annually in New Jersey. However, the current system is fragmented and time-consuming. The MIDS replacement project will move the data submission to an Electronic Data Interchange (EDI) version that imposes stringent edits prior to delivering the data to the state, thus eliminating the frequent corrections imposed on the hospitals under the current system.

3. **Nursing Home Quality Initiative**
This project will pilot a partnership between the State and 20 long term care facilities for the submission of standardized data in order to develop tools in the support of Continuing Quality Improvement (CQI) efforts. The Robert Wood Johnson Foundation has also awarded a $712,000 grant to DHSS to further support this initial pilot project.

4. **Provider Network**
For fiscal 1997, 24 acute care hospitals were given a grant to establish internet access. The goal of this project is to evaluate the feasibility of eventually linking all providers in the state using secure transmission modes over the internet. This first step will permit easy communication among providers and help promote more interaction and sharing of information. The long-term goal is to successfully respond to the tremendous administrative savings identified in the HINT report.

In the New Jersey Legislature, Assembly Bill A1476 (Senate Bill S50) establishes a Health Information Electronic Data Interchange Advisory Council. This bill, and eight other associated bills were first introduced in February 1996 and as of May 1997, six Senate bills, including S50, had passed while all others remained in committee. Currently, all Assembly versions of these bills remain in committee.

As a result of New Jersey's Health Maintenance Organization (HMO) rules (N.J.A.C. 8:38), the Health Data Committee (HeDaC) was formed to advise the Commissioner of Health and Senior Services on a data reporting system that will collect standardized, reliable and comparable information for all HMOS in New Jersey (*The Issue Brief Review*, 1997). HeDaC has collected 1995 information for nine selected HEDIS measures (such as childhood immunizations and diabetic retinal exams) from each HMO. The goal is to produce "report cards" from the data collected in order to enable consumers and purchasers to make informed choices about HMO plans and services.

One example of the private sector's involvement with health care quality data is the creation of the New Jersey Health Care Quality Institute by the Health Care Payers Coalition of New Jersey. The Institute's goal is "to create a forum where providers, payers, consumers and insurers can work cooperatively to share health information and to research, develop and implement high health care standards" (New Jersey Health Care Quality Institute, 1997). The Institute plans to identify, develop and apply standardized methodologies to measure, improve upon and communicate health care quality in New Jersey.

CONCLUSION

At this point in the health care evolutionary process, it once again falls to state-level policy and decision makers to meet the challenge of deciding on which direction and approach to take regarding health data and information systems. It can be argued that in a competitive environment with diminished regulatory controls in place, state government must take responsibility for wide dissemination of information to the public. Funding to provide the tools to do so remains problematic. One health data expert from the state of Maryland pointed out that historically, the majority of the funding dedicated for health data activities at the state level has been earmarked for data collection as opposed to data analysis and dissemination for the practice of policy-making. As updated technology — such as electronic communication tools, access to the Internet and streamlined information systems — has provided more technical and fiscal flexibility in the field of health information, is New Jersey in a position to commit more of its funding to the analysis and dissemination of health information for its policymakers?

As is evident from the variety of different models in operation across the 50 states, the difficulty lies not in identifying what options are available, but in selecting and developing the ones most suitable to state culture and its unique health care environment. Unlike the medieval alchemists, we can turn the "lead" of health statistics into the "gold" of relevant and meaningful health information to guide public policy and decision-making. The questions to be answered are how and in what ways we want to do so.

Just as in the movie Contact, the key to finding the primer in order to translate the transmitted data was to move beyond a linear solution to one which was multidimensional; the solution involved not only intelligence and technology, but vision and risk to look beyond traditional ways of problem-solving. The development and implementation of integrated health information systems which can guide policy-making in a reliable and rational way requires taking such risks in problem-solving.

In a recent article — "Smart Technology, Stunted Policy: Developing Health Information Networks" — sociologist Paul Starr cautioned that the technological capabilities are available to us to create sophisticated health information systems, yet the policies to develop and to use these health information systems so as to produce reliable information about the cost and quality of health care continue to lag behind. Across the country, various private business and industry groups as purchasers of health care, as well as health care provider groups, are aggressively moving forward in their gathering of health information in order inform their administrative and purchasing decisions. It is left to government to decide the type of role it will take in this dynamic environment and to establish how and in which ways it will proceed.

APPENDIX A

Table 1, below, exemplifies one type of formatting of "policy relevant" information that is available on the New York State Department of Health's on-line database accessible through the Internet. Several characteristics emerge when analyzing how the data is presented on the one-page table: states are listed in order of those with the highest level of uninsured to those with the lowest (rather than in alphabetical order); the breakdown of each category of insurance coverage — public, private and uninsured — is shown in real numbers and percentages of the population; and national averages and percentages are given. Both inter-state and national comparisons can be made, as well as regional comparisons. The source is clearly given, so that analysts are made aware of any limitations inherent in the data source; finally, a policy-maker can access another site on the database for information on a specific category, for example, how does public insurance coverage break out in terms of Medicare and/or Medicaid coverage for a specific state's population.

Table 1
Source of Insurance Coverage by State, 1994

	Total		Public		Private		Uninsured	
	#	%	#	%	#	%	#	%
Louisiana	4,254,754	100	1,208,139	28.4	2,031,756	47.8	1,014,859	23.9
Oklahoma	3,330,166	100	724,701	21.8	1,820,716	54.7	784,750	23.6
New Mexico	1,624,821	100	370,150	22.8	897,737	55.3	356,934	22.0
Texas	18,293,648	100	3,868,234	21.1	10,445,013	57.1	3,980,401	21.8
Dist of Col.	597,120	100	181,226	30.4	292,440	49.0	123,454	20.7
Arizona	4,005,293	100	879,583	22.0	2,316,193	57.8	809,518	20.2
California	32,067,905	100	8,071,573	25.2	17,663,414	55.1	6,332,918	19.7
Arkansas	2,426,899	100	660,988	27.2	1,287,961	53.1	477,949	19.7
Florida	14,138,235	100	3,818,531	27.0	7,552,011	53.4	2,767,692	19.6
Georgia	6,863,161	100	1,386,608	20.2	4,214,383	61.4	1,262,170	18.4
W. Virginia	1,807,952	100	572,202	31.6	904,257	50.0	331,493	18.3
Nevada	1,445,124	100	240,250	16.6	943,363	65.3	261,510	18.1
Mississippi	2,589,226	100	795,011	30.7	1,332,037	51.4	462,178	17.9
Alabama	4,169,853	100	1,033,279	24.8	2,417,423	58.0	719,151	17.2
So Carolina	3,641,620	100	868,025	23.8	2,157,503	59.2	616,092	16.9
Montana	850,192	100	201,935	23.8	518,336	61.0	129,921	15.3
Wyoming	483,742	100	87,323	18.1	323,812	66.9	72,608	15.0
Idaho	1,145,850	100	231,838	20.2	744,096	64.9	169,917	14.8
Oregon	3,079,122	100	619,490	20.1	2,007,023	65.2	452,609	14.7
N Carolina	6,741,150	100	1,578,870	23.4	4,216,178	62.5	946,102	14.0
New York	18,240,582	100	4,874,992	26.7	10,829,396	59.4	2,536,193	13.9
New Jersey	7,972,354	100	1,706,044	21.4	5,177,408	64.9	1,088,902	13.7
Maryland	4,928,590	100	1,079,758	21.9	3,183,732	64.6	665,100	13.5
Delaware	713,999	100	139,994	19.6	478,551	67.0	95,455	13.4
N Dakota	626,930	100	127,573	20.3	415,631	66.3	83,726	13.4
Alaska	571,431	100	107,332	18.8	387,881	67.9	76,218	13.3
Tennessee	5,105,335	100	1,301,293	25.5	3,131,452	61.3	672,590	13.2
Virginia	6,497,087	100	1,035,237	15,9	4,614,023	71.0	847,827	13.0
S Dakota	717,316	100	159,389	22.2	464,641	64.8	93,286	13.0
Kansas	2,500,222	100	558,937	22.4	1,623,289	64.9	317,996	12.7
Washington	5,236,172	100	1,050,935	20.1	3,524,211	67.3	661,026	12.6
Colorado	3,567,615	100	662,227	18.6	2,456,200	68.8	449,188	12.6
Illinois	11,742,511	100	2,586,348	22.0	7,680,894	65.4	1,475,270	12.6
New Hamp.	1,130,737	100	183,508	16.2	805,819	71.3	141,411	12.5
Kentucky	3,750,016	100	1,114,248	29.7	2,167,723	57.8	468,044	12.5
Missouri	5,196,038	100	1,232,887	23.7	3,330,330	64.1	632,820	12.2
Vermont	588,839	100	139,496	23.7	379,036	64.4	70,307	11.9
Indiana	5,766,144	100	1,285,303	22.3	3,793,525	65.8	687,315	11.9
Nebraska	1,644,004	100	328,948	20.0	1,119,851	68.1	195,205	11.9
Mass.	6,003,415	100	1,350,327	22.5	3,949,956	65.8	703,132	11.7
Utah	1,907,786	100	277,389	14.5	1,415,595	74.2	214,802	11.3
Michigan	9,572,610	100	2,456,144	25.7	6,047,167	63.2	1,069,299	11.2
Ohio	11,278,006	100	2,659,542	23.6	7,361,831	65.3	1,256,633	11.1
Hawaii	1,138,183	100	222,926	19.6	788,992	69.3	126,265	11.1
Maine	1,278,210	100	319,022	25.0	817,534	64.0	141,653	11.1
Penns.	12,089,927	100	3,026,516	25.0	7,760,009	64.2	1,303,402	10.8
Rhode Is.	968,965	100	248,125	25.6	621,358	64.1	99,483	10.3
Minnesota	4,353,732	100	930,030	21.4	2,982,829	68.5	440,873	10.1
Conn.	3,259,244	100	641,162	19.7	2,291,386	70.3	326,696	10.0
Iowa	2,814,728	100	573,490	20.4	1,981,176	70.4	260,063	9.2
Wisconsin	5,036,035	100	1,033,866	20.5	3,562,000	70.7	440,169	8.7
Total #	259,752,595		60,810,944		159,229,078		39,712,572	
%		100		23.4		61.3		15.3

Source: Current Population Survey, 1994

APPENDIX B: THE NATIONAL SCENE

II. NATIONAL DATA INITIATIVES - AN UPDATE

Regarding the standardization and coordination of health data, national efforts continue to focus not on producing more data, but on the development of core data sets and the sharing of accurate and reliable data. Over the past two years, the National Committee on Vital and Health Statistics and the U.S. Department of Health and Human Services have moved forward with their efforts to identify, define and implement standardized data sets for health care data. The Health and Human Services Data Council is conducting continued activities to coordinate all health and non-health data collection and analysis activities in the Department through an integrated health data collection strategy, coordination of health data standards, and health information and privacy policy activities.

Recently, the Council has been charged with the implementation of the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act of 1996. These provisions call for the adoption of technical standards for health data communication are designed to "improve the efficiency and effectiveness of the health care system. . .through the establishment of standards and requirements for the electronic transmission of certain health information (Mendelson & Salinsky, 1997). Issues of protecting the privacy of health information are central to the discussion of standardizing, coordinating and sharing health data (DHSS Secretary Donna Shalala, *Address, National Press Club*, July 31, 1997).

Under the health and welfare provisions of the Federal 1997 Balanced Budget Act, a State Children's Health Insurance Program is established under new Title XXI of the Social Security Act to provide states $24 billion in federal funds for 1998 to 2002. As part of the funding mandates, states are required to collect data, maintain records and furnish reports to the DHSS for monitoring of administration and compliance, as well as for evaluation and comparison of state plan effectiveness for this program.

Until recently, the National Center for Health Statistics conducted the only annual national health care survey — the National Health Interview Survey (*Issue Brief*, Center for Studying Health System Change, No 8. April 1997). The Agency for Health Care Policy and Research (AHCPR) has now created the Medical Expenditure Panel Survey to replace the National Medical Expenditure Survey (which was conducted only periodically). The Medical Expenditure Panel Survey (MEPS) will be conducted annually and will permit continuous monitoring of access to health care, along with tracking of health care utilization, health insurance coverage and health care expenditures (Ibid).

The National Association of Health Data Organizations (NAHDO), which coordinates the activities of health data organizations and groups throughout the country, continues to hold as its priority goals: data standardization, performance measurement; data and information dissemination, confidentiality, privacy and data security (NAHDO, 1996 *Annual Report*). Through collaborative work with the Center for Health Research and Communications, NADHO launched a web-site clearinghouse of information on health information sources: the National Health Information Resource Center (NHIRC). As a clearinghouse about health information systems and data, its services include health data sites and links; health data project abstract files; and on-line conferences and policy forums, on subjects such as privacy and data standards. Through NHIRC, for example, one can find out what the state of South Carolina is doing in regard to its public health information database and whether or not it is linked into a Medicaid database to track childhood immunization rates. (Reference is made to: www.nhirc.org.)

III. NATIONAL PERFORMANCE AND OUTCOMES MEASUREMENT INITIATIVES

With the evolution of the health care system into a deregulated environment and the stronger presence of managed health care, the importance of outcome measures to assess quality and appropriateness of care, access and patient satisfaction has come to the forefront. On the Federal level, the Agency for Health Care Policy and Research (AHCPR) is working with The Lewin Group to conduct a Consumer Assessment of Health Plans Study. The project is involved in designing, field-testing and disseminating consumer assessments of health plans and services to help consumers and purchasers make choices among competing health plans in a given health insurance market. One component of the project is to develop a model of consumer decision-making (The Lewin Group, *Newsletter*, 1997).

The three large-scale projects described below represent the leading edge in developing performance measurements and quality outcomes on the national level. The National Committee for Quality Assurance (NCQA), the Foundation for Accountability (FACCT) and the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) are each engaged in activities in developing and disseminating standardized methods for evaluating performance of health care providers and/or plans. The goals of their projects are to develop and use data for multiple purposes, which can be used by purchasers and consumers to make informed health care decisions and by providers and plans to identify performance, practice strengths and weaknesses, and areas for improvement.

The Foundation for Accountability (FACCT)

The Foundation for Accountability, a coalition of public purchasers, private purchasers and consumer organizations representing over 70 million Americans, continues with its efforts to strategize ways for applying outcomes research in the "real world." Since its establishment in 1995, FACCT's efforts towards developing quality standards have included identifying, reviewing, selecting and (ultimately) endorsing specific sets of quality measures. Sets of measures that have been endorsed by FACCT include those for diabetes, breast cancer, asthma and major depression. Once measures are adopted by FACCT, it promotes their use by working with representatives of standard-setting organizations (e.g., NCQA, JCAHO) to adopt the measures and by encouraging business/purchaser coalitions, independent employers, Medicare HMOs and Medicaid to use the measures in their contracts. FACCT has found that there continue to be multiple barriers to widespread use of its adopted measures. These barriers include diversity in the forms of health care delivery and financing; the concern of purchasers to adopt any single quality measure in the absence of a definitive "gold standard"; and the inadequacy of many data systems to integrate new quality measures into their operations (Foundation for Accountability, Cybertext, 1997).

The National Committee for Quality Assurance (NCQA)

The National Committee for Quality Assurance, an independent, not-for-profit organization that assess the quality of health maintenance organizations, is a partnership among purchasers, consumers and health plans. In its efforts to measure and report upon the quality performance of health plans, NCQA is using a two-pronged approach to provide information about quality: (1) a full-scale accreditation process, and (2) performance measurement through its HEDIS (Health Plan Employer Data and Information Set) initiatives.

The development the HEDIS program is an ongoing process in which various versions (HEDIS 2.0; 2.5 and 3.0) are released; each version includes different types and sets of quality measures. The program's objective is to build a national capacity for measurement through which comparisons across plans can be made. The HEDIS system also includes a Medicaid managed care-specific set of measures. In March 1997 HEDIS 3.0, volume 4 — "A Road Map for Information Systems" — was released by NCQA. The report identifies gaps in current health plan data systems that limit performance measurement efforts, including incomplete data, lack of quality control, lack of automation of data systems, and an inability to share data between systems; it offers recommendations for implementing comprehensive health data management systems over the next 10 years. NCQA's future goals for HEDIS include the evaluation of non-HMO types of managed care organizations (at present the technology to evaluate these organizations does not exist) and evaluation of performance in a fee-for-service environment.

NCQA's Quality Compass is a national database of comparative information about the quality of the country's HMO plans; it contains both HEDIS and accreditation information from 250 plans and supports plan-to-plan comparisons in such areas as: financial performance, utilization of services and quality of care. Quality Compass does not include all HMO plans, nor does it include non-HMO plans, such as preferred provider organizations. Examples of categories measured include: mammography screening rates; access to health care services rates and childhood immunization rates.

The Joint Commission on Accreditation of Health Care Organizations

As it accredits more than 14,000 health care organizations, including health care networks, hospitals, nursing facilities and clinical laboratories, the Joint Commission on Accreditation of Health Care Organizations (JCAHO) is also involved in efforts to measure the performance of provider organizations. JCAHO is involved with the health care network accreditation program, which measures performance for networks and health plans that offer integrated comprehensive health services. The type of accreditation process moves beyond JCAHO's traditional accreditation approach (in which process and structure measures are evaluated every three years) to more of a continuous monitoring and accreditation of the network's outcomes and capabilities. These capabilities include not only clinical performance, but also patient satisfaction and patients' functional health status.

JCAHO's IMSystem is an indicator measurement system and database designed to measure the performance of health care providers; to allow the organizations to use data for quality improvement and to generate reports on quality for patients, purchasers and regulators (JCAHO, Cybertext, 1997). Designed to support the accreditation process, the system collects data abstracted from patient records, risk adjusts it and stores it at the level of the individual patient. At present, the IMSystem size is limited; it continues to expand to include more case records and participating hospitals.

While all three of these quality data systems have been evolving since their inception, they are confronted by the challenges of developing and implementing new integrated, standardized systems in the face of a past framework of fragmented and non-standardized collection and reporting systems. Further, while these efforts are moving Americans closer to more reliable forms of performance outcomes and quality indicators, the NCQA, HEDIS and JCAHO initiatives have created yet a new variety of "alphabet soup" in an already confusing health care environment. At this stage in the process, there is no one reliable "report card" on plan quality that can serve the information needs of consumers, providers and/or purchasers. The absence of such a standard places considerable burden on states in their roles as purchasers and regulators in order to hold health plans accountable for the quality of health care provided (Riley, 1997).

IV. NATIONAL HEALTH INFORMATION AND POLICY INITIATIVES

There are several projects and initiatives on a national level which are addressing the issue of data integration and the dissemination of information in an usable form to respond to questions asked by policymakers.

Registry of State Data Integration Efforts

The U.S. Department of Health and Human Services (through The Lewin Group) has developed a Registry of State Data Integration Efforts that focuses on state data policy activities and key state contact persons. A review of Registry activities across the 50 states indicates that there is broad variation as to where each state stands vis-a-vis its health information activities. This variation derives from multiple factors, particularly because each state has its own health and medical care delivery infrastructure and socio-economic variables. In general, the types of projects and initiatives currently operating at state level include: case management systems; community profiles; data warehousing; decision support systems; registries for cancer, immunization, births and deaths; public health information system projects; maternal and child health systems and Medicaid and WIC systems. (Reference is made to: http://aspe.os.gov/.)

Information for State Health Policy (InfoSHP)

An example of a partnership project to facilitate turning valuable health statistics into workable information for state policymakers is the Robert Wood Johnson Foundation's national grant program, Information for State Health Policy (InfoSHP). Although acknowledging that there are numerous examples of how state data agencies can support decision-making successfully, InfoSHP project analysts maintain that to date, no single state appears to have a comprehensive health statistics system that is responsive to policymakers' needs (InfoSHP, 1997). Quick responses are required to the broad range of questions posed by policymakers; yet, data collection agencies in most states do not have the human and/or technological support and resources necessary to provide answers to these questions. The InfoSHP project also has found that in many states, the agencies responsible for data systems do not coordinate with those responsible for policy development and program management.

In Phase II of the project, seven states — Arkansas, California, Mississippi, New York, North Carolina, South Carolina and Wisconsin — are awarded implementation grants to help state policymakers make the most informed decisions about health care programs by improving the integration of data, long-range planning efforts and ongoing policy activities.

In a 1997 evaluation of the first four years of the InfoSHP program, researchers found that: "[S]tate information initiatives face the daunting challenge of demonstrating relevant short-term results while garnering support for longer-term investments in data systems and infrastructure" (Feldman et al, 1997). The study found that in the dynamic environment of state health policy making, data needs are immediate; skill at bridging gaps between data producers and data users, and the ability to tailor information strategies to state-specific needs, are "critical in improving the use of information for policy making" (*Advances*, Issue 2, 1997). The evaluators also reported that the most successful states pursued a two-track strategy: improving analytical capacity while taking advantage of "open policy windows" (Ibid). These same states focused their resources on "translating existing data into visible products that could show selected government, business or advocacy groups the value of information for highlighting a specific policy problem or framing a specific policy issue" (Id).

Urban Institute — Assessing the New Federalism

One significant component of the Urban Institute's policy research project — "Assessing the New Federalism," is its 50-state database which will incorporate state-specific data in five main areas: health; income security; child well-being; state fiscal and political conditions, and social services. The data presented includes measures of budget growth or decline, tradeoffs among major spending categories and indicators of "how programs are changing." For example, welfare programs are being tracked in terms of changing benefit levels, eligibility rules and time limits. Information is being collected from various government agencies and from other data sources which include the National Conference of State Legislatures and the National Association of State Budget Officers. The Urban Institute is also conducting surveys to collect data for inclusion in its database. (Reference is made to: www.urban.org for access to the 50-state database.)

The Darmouth Atlas of Health Care, available in book, diskettes and CD-ROM, offers a rich variety of data in its analysis of the country's 306 hospital referral regions and 3,400+ local health care markets or hospital service areas. The *Atlas* also provides nine regional supplements for comparisons along issues such as use, efficiency and cost of health services (Robert Wood Johnson Foundation, *Perspectives,* June 1997) National, regional and local comparisons have yielded results pointing to some striking differences in rates of medical care usage. For example, the Dartmouth study looked at the percentage of inpatient breast cancer surgery in Medicare women that was breast-sparing in nature. Breast-sparing surgery was more widely and commonly used in the Northeast than any other place in the country; regionally, its use was lowest in the South, Midwest and Northwest (Ibid).

In meeting the challenges of producing and disseminating state-specific health policy information, several national organizations and research groups are involved in research and educational activities. These include The Alpha Center; The National Academy of State Health Policy; The Rockefeller Institute; The Intergovernmental Health Policy Project (now aligned with the National Council of State Legislatures) and its newly created Forum for State Health Policy Leadership, designed to bring together selected state legislators active in developing innovative state health policy.

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