

## THE ROLE OF STATISTICS IN THE DEVELOPMENT OF HEALTH CARE POLICY

Dorothy P. Rice, National Center for Health Statistics

The need for and the development of a National Health Policy has generated much discussion and debate in the United States in recent years. The consensus of public and private interests on the need for a health policy derives in large measure from the recent escalation of medical care expenditures. In fiscal year 1950, medical care expenditures amounted to \$12 billion and represented 4.6 percent of the Gross National Product (GNP) and by Fiscal Year 1975, Health spending rose to \$118 billion and consumed 8.3 percent of the GNP (Mueller). Although data for the year ending June 1976 are not yet available, the projections are for about \$135 billion and 8.5 percent of GNP.

### What is Health Care Policy?

Rising costs are a continuing and persistent characteristic of the health care industry. "The health sector bears the dubious distinction of having suffered from intractable inflation for years, long before the rest of the economy discovered it" (Russell). Coupled with the concern about inflation is the concern about the organization and provision of medical care services. In the 1960's, health care came to be perceived as a right rather than a privilege (Cooper, White). The enactment of the Social Security Amendments of 1965 that established the new public programs-- Medicare and Medicaid--established a policy of providing coverage and care for two major population groups--the aged and the poor. That milestone legislation enunciated another policy, however. Its preamble prohibited Federal interference with "The practice of medicine or the manner in which medical services are provided."

The infusion of public dollars into the medical care system accompanied by the perception of the right to medical care but without regard to the shortcomings of our delivery systems, has placed a strain on the health care delivery system resulting in fragmentation of services, unequal access to health care and lack of continuity of care (Austin, Ball, Seward). These converging forces have produced a lively debate on the need to intervene in the organization and delivery of medical care services to effectively guide the use of the Nation's resources and fulfill the expectations and perceptions of the "right to health care."

A number of investigators have commented on the ability of medical care to favorably influence health. Their conclusions indicate that there is often a lack of positive correlation between the two (Abel-Smith, Fuchs, Illich). We obviously cannot do without medical care, for a cessation of all medical care would surely be followed by a worsening of health status. Nevertheless, questions are being raised and actively investigated as to whether increments or decrements in the amount of medical care result in improvement or deterioration in the level of health (Rice, Wennberg).

The recognition of a "health care crisis" undoubt-

edly had its roots in the escalation of medical care prices and expenditures in the late 1960's. The President's health message of 1971 and the White Paper "Towards a Comprehensive Health Policy for the 1970's" issued in May 1971 stressed the need for an "interlocking strategy" in solving the medical care problems facing the Nation. The annual "Forward Plan" for health issued in the past several years by the Assistant Secretary for Health also emphasized the multifaceted approach to health care policy. The National Health Planning and Resources Act of 1974 (Public Law 93-641) sets "equal access to quality health care at a reasonable cost" as a National priority. The first provision of this law calls for the issuance of National guidelines for health planning, which set forth National Health planning goals and standards relating to the appropriate supply, distribution and organization of health resources.

I have sketched this background in the development and emergency of health care policy in some detail to emphasize the recognition that health care policy is comprised of an inter-related and systematic approach to meeting the challenge of assurance of the right to health care. Thus, it must evolve from a set of policies that address the health care problems that face the Nation, including:

1. Escalating costs of health care and the concomitant burdens of financing medical services;
2. Variations in demand for and inequities in access to medical care services that partly arise from the maldistribution of medical care resources;
3. Uneven quality of medical care that emerges from the inappropriate application of medical knowledge, without regard to the balance between the hazards inherent in medical intervention and the benefits derived from it.

### The Need for Data

The development of a health care policy or policies dictates the need for collection, analysis, and dissemination of data in all the above areas. The 1960's and 1970's have seen a considerable number of program developments that, on the one hand, have produced a tremendous amount of information; on the other hand, they created additional needs for both general purpose and program specific data essential to health management at every level of government.

Finagle's laws on information state: "The information you have is not what you want; the information you need is not what you can obtain" (Murnaghan). In spite of that pessimistic outlook on the fulfillment of data needs, I believe that the development of a coordinated, systematic, and responsive data base is essential and feasible for government to make informed decisions for policy development and planning, to as-

sess the impact of these decisions, and to operate its programs effectively. Just as hard data, both economic (such as GNP and CPI) and social (health utilization and longevity data) have indicated the need and possible directions for developing a set of health care policies, so will statistical information be important in implementing and monitoring the policies and identifying areas for modifications.

Past experience has shown that the need for "hard data" is a function of our emerging modern society (Hauser). As society's demand for an improved standard of living brought about new social processes, the government increased its functions to deal with these expansions. This expansion will continue; new public policies of increasing sophistication can be expected (Kahn, Abelson). The development of these health policies will reflect this dynamic interaction between social change and governmental functions.

One of the most significant challenges is the development of data systems capable of satisfying the multiple needs for data and providing the data required for evaluation of the impact of health programs, while keeping respondent burden reasonable. The needs for data extend beyond the Federal government to State and Local governments and private providers and third party payors. They all need reliable, timely, and comparable data and analyses which describe the health status of the population (including statistical analyses of determinants of health and disease); the availability of resources; the accessibility and use of services, the costs of services and resources, the sources of funding, and the quality of care. The lack of such statistics severely limits our capacity to plan, manage and evaluate our tremendous investment in health resources and delivery systems. Clearly then, the development of a coordinated, systematic and responsive data base is essential.

#### Organization of Health Statistics Programs to Meet Data Needs

How is the health statistical community responding to the needs of policymakers? The history of Federal statistical activities goes back to the last century when information on births and deaths was collected periodically by the Bureau of the Census. This function was moved to the Public Health Service in 1946. The National Health Survey Act of 1956 authorized a continuing survey and special studies of sickness and disability in the U.S. population as well as methodological research. Since those days, the health statistical programs have been continually adapting to better meet the emerging needs of an expanding community of data users. These users are considerably more sophisticated than in the past. They demand considerably more information as well as more knowledge of the limitations of the information. We have to be especially careful not to measure the things that are easy to measure rather than those which would be helpful simply because those which would be more helpful cannot be measured well (Tukey)

My thesis is a simple one: We are developing a National and systematic approach to meeting the needs of policymakers at the Federal level. At the same time, we are cognizant of the State and local needs and have begun to address them. I would like to first briefly outline the developments in the Department of Health, Education, and Welfare.

#### Health Data Policy Committee

In recognition of the complexity of the health statistics systems and the widespread distribution of responsibility within DHEW, a Health Data Policy Committee was established in April 1974 to advise the Assistant Secretary for Health on current and long-term data needs for planning and management, on policies and procedures for coordination of health statistics activities, on proposals for major new health statistics systems, and on uniform minimum basic data sets.

The Committee has developed into an effective vehicle for a coordinated approach to data oriented health policy issues. It provides an internal forum for discussing and resolving specific issues and a focus within the Department for liaison and cooperative arrangements with other agencies. Active participation of representatives from the Office of Management and Budget, the Department of Defense, and the Veterans Administration provides the Department with valuable information on the related experience and data requirements outside of the Department.

#### The U.S. National Committee on Vital and Health Statistics (USNCVHS)

A second committee, USNCVHS, established by the "Health Services Research, Health Statistics, and Medical Libraries Act of 1974, P.L. 93-353, provides a communication link between the public and private sector. This committee is the primary outside advisory group on matters of health statistics to the Secretary and the Assistant Secretary for Health. With staff support from the NCHS, the Committee stimulates studies and provides advice on statistical health problems of National or international interest, on health statistics and health information systems, and on a range of health statistical issues and activities that affect health care policies.

These two advisory bodies--the HDPC and the USNCVHS--provide a balanced and strong influence in the development of systematic statistical systems and mechanisms for assuring better coordination, integration, and accountability of these systems.

#### A Framework for Health Statistics Activities

P.L. 93-353 designates the NCHS as the focal agency for the collection and dissemination of

the following data on the Health of the Nation:

(A) The extent and nature of illness and disability of the population of the United States, including life expectancy, the incidence of various acute and chronic illnesses, and infant and maternal morbidity and mortality,

(B) The impact of illness and disability of the population, on the economy of the United States, and on other aspects of the well-being of its population,

(C) Environmental, social, and other health hazards,

(D) Determinants of health,

(E) Health resources, including physicians, dentists, nurses, and other health professionals, and the supply of services by hospitals, extended care facilities, home health services, and other health institutions.

(F) Utilization of health care, including ambulatory health services and services of hospitals, and other institutions,

(G) Health care costs and financing, including the trends in health care prices and cost, the sources of payments and Federal, State and local governmental expenditures for health care services, and

(H) Family formation, growth, and dissolution.

In its wisdom, the Congress clearly recognized the need for the production of baseline, general purpose statistics to provide a broad range of data for the development and implementation of health care policy. It is also noteworthy that in the original National Health Survey Act of 1956, Congress recognized the need for quality data. In addition to specifying the kind of health data needed, Congress provided "For studying methods and survey techniques for securing such statistical information with a view toward their continuing improvement.

#### The Annual Report on the Nation's Health

P.L. 93-353 also specifies that the National Center for Health Statistics (NCHS) and the National Center for Health Services Research (NCHSR) assist the Secretary of DHEW to prepare and disseminate an annual report to the President and Congress. This annual report on the Nation's health entitled Health: United States, the first volume of which was issued in January, 1976, is an on-going mechanism for organizing the available data. Information from the various data collection systems in NCHS are combined with that from other components of the Federal Statistical System, including, for example, expenditure data from the Center for Disease Control, manpower statistics from the Bureau of Health Manpower, and the medical care price data from the Bureau of Labor Statistics.

Non-Federal statistics such as those collected by the American Medical Association and the American Hospital Association were also included.

Work is proceeding on the second annual report which will summarize developments in the past year, and will analyze specific health issues and problems. Analytical chapters planned include such subjects as the health of children, hypertension, and current functioning and financing of the hospital industry.

#### Addressing Current Policy Issues

To illustrate further how the DHEW is responding to the data needs of policymakers in the health area, I will briefly discuss a few current illustrative issues and the emerging data requirements and implementation.

1. National Health Insurance - One of the major issues in the development of a health care policy is National health insurance. To provide Congress and the President with information about various options for financing health care, NCHS and NCHSR are collaborating on a Medical Care Expenditures Survey, that will begin in January 1977. It will produce National and regional data on utilization of and charges for medical care services, including hospitals, physicians and dentists, and on such expenses as drugs. Although National health care expenditures in the United States total about \$125 billion in Fiscal Year 1976, little is known about the distribution of these expenditures, and what medical care services are used, who uses them, and who eventually pays the bill. The data from this survey will give information that relates to one of the major health policy issues facing the Nation. The information we are collecting and will analyze will help us make informed decisions about National health insurance and other major health issues. We will obtain vitally needed information about health insurance coverage, access to health services, and financing health care. The study will lay the groundwork for addressing and analyzing patterns of health services use and payment for future large scale health insurance programs.

2. Quality of Care - This has become one of the central health policy issues of the 1970's: The Professional Standards Review Organizations' program has been launched to develop a Nationwide system of hospital quality assurance. This quality assurance effort is expanding to include non-hospital institutional care and ambulatory care, and may well encompass care reimbursed by private health insurance as well as governmental programs. It has been recognized that the need for data is crucial to the successful implementation of the PSRO program. No issue better illustrates the current controversies besetting the program than the question of how data systems are to be developed, and who will have access to what type of information.

3. Health Planning - Up to this point, I have discussed health statistics at the National level. However, reliable health statistics at the State and local level are also necessary (Rice, Densen). Passage of the Health Planning and Development Act of 1974 emphasizes this need. As a result of this law, P.L. 93-641, the U.S. has been divided into 212 health service areas; within each of these, the law establishes a health systems agency among the functions of which are the compilation of available data pertaining to health status and its determinants and the utilization of health services. The law also specifies that the staff of each agency shall have expertise in the "gathering and analysis of data."

This mandate provides many challenges. For example, what is health and how does one measure health status? How do we measure utilization? Are there barriers to utilization and how do we identify them? What data are available that are suitable to assess these problems and how accurate are the data? Enactment of the Health Planning and Development Act of 1974 emphasizes the need for the statistician to provide timely and accurate data bases and skillful analysis and interpretation of the data at the State and local level.

A major resource to meet the needs of health systems agencies is the Cooperative Health Statistics System (CHSS). The CHSS is designed to provide the framework for a coalition among the various levels--National, State and Local, for the production of health statistics. Input is obtained from data users at these geopolitical levels regarding data they need, turnaround time they require, and the required frequency, reliability, etc. The agreed-upon data items are collected by the level best equipped to collect them and the data are then shared with all users. NCHS has the responsibility for providing National leadership by coordinating the efforts among Federal agencies and between the Federal government and the States, and in assuring the quality and comparability of data collected. The CHSS will help mold the current fragmented data collection activities throughout the country into a cohesive system. This should result in savings in data collection costs, a greatly reduced burden on data providers, and more important, data will be comparable and in the requisite detail for most uses by all participants in the system.

We in NCHS are convinced that the full potential of the Cooperative System will be reached most quickly and efficiently by the development of strong, well-staffed State Centers for Health Statistics in each State. These centers would serve as focal points for the assembly and analysis of all health data and have responsibility for primary data collection and activities for at least one of the statistical components of the System. The centers should also have the capacity for analysis of health-related data, from whatever source, and be able to pro-

vide consultation to planning agencies and other users on the limitations and potentials of available data as well as on needs for additional information and how it can be secured. Several states now have such centers, and we are hopeful that others will follow their lead.

#### The Statistician's Role

But can one talk about the role of statistics in developing policy, whether in health or in any other field, without talking about the responsibilities of the statistician? Statistical information is generated to be used; without a statistical interpreter to explain such characteristics as reliability, precision and accuracy, data are weak, sometimes misleading and easily misused. Borrowing from Sir Claus Moser's speech at last year's ASA meeting the "...Foremost responsibility (of the statistician) is to contribute to more enlightened and efficient 'decisionmaking' through the provision of a timely and accurate data base and through the fullest possible exploitation of our skills in analyzing and interpreting the data." This responsibility is key whether we are government statisticians at either the Federal, State or Local level, or working in academia or in private industry.

The statistician's responsibility whether employed in the public or private sector, is to two audiences: 1.) the users of his product and 2.) the suppliers of his raw material (Frankel). In discussing the development of policy, the focus is on the use of statistical information. Data may be used in health decisions concerning the level of funding of community mental health centers, of the new health systems agencies, and of medical facilities. Data may also indicate tradeoffs for resource allocation.

The statistical environment appears to be shifting. Until recently, the health statisticians have viewed their responsibility primarily as one of providing accurate data. However, with the increasing demand for hard data to assist in the decision-making process, it is no longer sufficient to provide accurate statistics. It is necessary to develop on this foundation of technical expertise a framework which expedites the provision of information. Thus, we need to consider new ways to provide data in a timely fashion and in an analyzed, packaged format. Among the various ways of providing timely data are data sharing, piggy-backing surveys, and anticipating user needs.

First, let me point out that with unlimited resources, i.e., money and manpower, getting statistics out in a timely fashion would be much less of a problem than it is now. However, the statistician rarely operates with unlimited resources. We are searching for innovations which enhance data production with minimal increased demand on resources. I have mentioned three ways--data sharing, piggy-backing, and

anticipating needs--let us examine more thoroughly and point out specific action in health data programs:

1. Data Sharing - As data become more costly to collect and our concern for respondent burden, alternative methods for obtaining the necessary information must be actively identified (Oaxaca, Dunn). The Health Data Policy Committee is working towards standardization of terminology and analytic conventions. While this will facilitate the multiple use of various data sets, the privacy and confidentiality of the respondent must be respected.

Data sharing involves not only collection but also the dissemination of such data. One such mechanism is through the timely development, distribution, and sale of data tapes.

2. "Piggy-backing" Surveys - By adding a few key questions to an on-going survey, time and costly implementation procedures can be spared. The forthcoming swine flu supplement to the Health Interview Survey is an example. Beginning in September, questions will be asked as to whether or not the respondent received the vaccine; if so, where, and if not, why not?

3. Anticipation of user needs - What is required is the foresight to put into place statistical systems that will be producing reliable and current information by the time the users become aware of their need for such data. We need statisticians who combine knowledge about our social and economic institutional structure with a high level of methodological sophistication. Such statisticians are at present in short supply. Certain alterations in the curriculum of our universities may be necessary if the demand for such statisticians is to be met.

In addition, Federal health statisticians are becoming increasingly aware of the uses and abuses of their products through communication channels of advisory groups such as the Health Data Policy Committee and the U.S. National Committee on Vital and Health Statistics. Experience has shown that various data collection agencies and users can cooperate to resolve issues in the provision of timely and relevant data.

We have identified three approaches to the provision of analyzed and packaged data:

1. New and Improved Methodology. As exemplified by the Medical Care Expenditure Survey, new surveys are time consuming to design and costly to implement. While new surveys may be the only way to answer some questions, they may not be the universal solution. More imaginative use can be made of existing data; one such NCHS project is to develop mortality indicators suitable for small area analysis.

2. Packaging of Information. Data needs

to be presented so that it becomes information rather than simply a collection of numbers. More extensive use should be made of media such as chart books and tabular compilations such as those presented in the Annual Report to Congress. The development of computerized graphics is also advancing. Software which provides sophisticated, multi-colored graphs is now available. NCHS is using one of these packages to produce a National Atlas of Mortality.

3. Statistical Training. In recognition of the importance of the communication between the statistician and the users of statistical information, in-depth programs, where students of various disciplines work together in a problem-solving environment are needed. Several universities (University of North Carolina, University of Arizona, and University of Hawaii) have established these types of degree programs. The NCHS also provides short-term training through the Applied Statistics Training Institute (ASTI) program.

With this type of training, statisticians become members of the policy formulating team. Involvement in the planning phases, whether in legislating new programs, setting up clinical experiments, or designing survey collection will prevent: 1.) some of the goal inconsistencies pointed out by the recent legislation; 2.) Casually or haphazardly collected data; and, 3.) missing data such as to encourage biases (Finney).

For the next few years, the statistician's prime responsibility will continue to be the provision of timely and accurate data bases and the interpretation of this data. However, user needs will grow in keeping with changing societal programs; even the characteristics of the audiences may change. So too, will the statistical environment change with the introduction of new resources and technological advances. Thus, the statistician must continually be aware of his audience and the environment in the provision of information for the development of public policy.

#### Privacy Protection

I have only alluded to the problems of confidentiality in my discussion thus far. I cannot end without expressing my concerns in this important area that is seriously affecting the statistical environment.

After years of struggling with the issues around confidentiality, NCHS--like other Federal government agencies--last year went to work to implement the Privacy Act of 1974. Actually, we had already for many years operated under a Section of the Public Health Service Act (Section 308 (d)) which precludes our using information for any purposes other than those for which it was collected and prevents our releasing information about individuals or establishments without their permission. While there were new and specific requirements in the Privacy Act which we had to meet, they gave us no difficulty.

Nevertheless, there remain some serious issues and concerns in the confidentiality area, including these:

1. The needs of our sister research and statistical agencies for legislation similar to ours, permitting them, too, to offer strong confidentiality protections (Duncan).

2. There are pressures for the passage of additional, stronger, and broader laws giving privacy protection, and there are, no doubt, some needs for them. But the laws must be written very carefully to assure that they do not unnecessarily hamper research.

3. More attention must be given to the problem of unintentional disclosures of information through statistical publications and through the release of public use micro-data tapes. Here, too, the rules must be written so that they do not unnecessarily impede statistical research.

4. As States begin to pass their own privacy laws, some of them very stringent, there is a pressing need to develop and promote model State laws which will provide needed protections but at the same time permit the efficient use of statistics to meet all the real needs for them at local, State, regional, and National levels.

The basic conflict between the citizen's right to privacy and society's need to know may never be resolved to everyone's satisfaction, but that is no reason not to keep trying. Our responsibility is to those who supply our raw material as well as to those who use our data.

In conclusion, I want to emphasize again that statistics and statisticians are going to play an increasingly important role in the development of health care policies. We are being asked to produce more data and more relevant data with resources that are not growing commensurately. We are being asked to aid in the interpretation and analysis of the data as well. It is an exciting prospect and one that will tax all our expertise and ingenuity.

#### REFERENCES

1. Abel-Smith, B., Value for Money in Health Services, Social Security Bulletin 37(7): 17-28, 1974
2. Abelson, Philip H., Editorial: More Laws, More Complexity, Science 192(4246): 1291, 1976
3. Andreano, Ralph L., Wiesbrod, B.A., American Health Policy, Chicago: Rand McNally College Publishing Company, 1974
4. Austin, Charles J., The Politics of National Health Insurance: An Interdisciplinary Research Study, San Antonio, Tx: Trinity University Press, 1975
5. Ball, R.M., Response to Medical Care Guarantees: Economics of Choice in, Implications of Guaranteeing Medical Care, J.G. Perpich (Editor), Washington, D.C.: National Academy of Sciences, 1975
6. Cooper, T., Do We Have a National Health Policy?, Journal of Occupational Medicine 17(10):625-627, 1975
7. Densen, Paul, Presentation at Public Health Conference on Records and Statistics: St. Louis, Missouri, June 1976
8. Duncan, J., Confidentiality and the Future of the United States Statistical System, American Statistician 30(2):54-59, 1976
9. Dunn, E., Social Information Processing and Statistical Systems--Change and Reform, New York: Wiley, 1974
10. Finney, D.J., Problems, Data, and Inference, Journal of the Royal Statistical Society A 137(Part1): 1-19, 1974
11. Frankel, L., "Statistics and People - The Statistician's Responsibilities" Journal of the American Statistical Association 71(353): 9-16, 1976
12. Fuchs, V., Who Shall Live?, New York: Basic Books, 1974
13. Hauser, P., Social Statistics in Use, New York: Russell Sage, 1975
14. Illich, I., Medical Nemesis, New York: Pantheon Books, 1976
15. Kahn, Herman, The Next 200 Years, New York: William Morrow and Co., 1976
16. Kendall, M., Statisticians--Production and Consumption, American Statistician 30(2): 49-53, 1976
17. Merriam, I.C., Social Security Policy Formulation and Health Research, International Journal of Health Services 3(1):59-68, 1973
18. Mueller, M.S., Gibson, R.M., National Health Expenditure, Fiscal Year 1975, Social Security Bulletin, 39(2):3-21, 1976
19. Murnaghan, J., Health Services Information Systems in the United States Today, New England Journal of Medicine 290(11):603-610, 1974
20. Oaxaca, F., President's Reporting Reduction Program, Statistical Reporter 76-10:185-190, 1976
21. Public Health Service, Forward Plan for Health, Washington, D.C.: DHEW, 1975

22. Public Health Service, Health Statistics Plan, Washington, D.C.: DHEW, 1975
23. Rice, D., Presentation at Public Health Conference on Records and Statistics, St. Louis, Missouri, June 1976
24. Rice, D.; Wilson, D., The American Medical Economy--Problems and Perspectives, forthcoming in Journal of Health Politics, Policy and Law
25. Russell, L., Inflation and the Federal Role in Health, in, Health: A Victim or Cause of Inflation?, New York: Prodist, 1976
26. Rutstein, D., Berenberg, W.; Chalmers, T.C.; Child, C.G.; Fishman, A.P., Perrin, E.B., Measuring the Quality of Medical Care: A Clinical Method, New England Journal of Medicine 294(ii):582-588, 1976
27. Seward, E.W., Medicare, Medical Practice, and the Medical Profession, Public Health Reports 91(4) 1:317-321, 1976
28. Tukey, J., Methodology, and the Statistician's Responsibility for Both Accuracy and Relevance, Statistical Reporter 76-13:253-262, 1976
29. Wennberg, J., National Health Planning Goals, in National Health Guidelines Volume III., Rockville, Maryland: Health Resources Administration, 1976
30. White Paper: Towards a Comprehensive Health Policy for the 1970's, Washington, D.C.: Department of Health Education, and Welfare, 1971
31. White, R.L., The Right to Health: The Evolution of an Idea, Iowa City, Iowa: University of Iowa, 1971