Issues in Developing Routine Data Sources for Health Planning

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PERSONS ENGAGED IN HEALTH PLANNING today are not being faced with a new set of conditions for which unanticipated demands for data are being made. Rather, they need to sort out from old demands those that could be met, in part or fully, by information from routine data sources and to examine under what conditions this might be accomplished. This is a repetitive process in which many in and out of government have struggled long before the current era of health planning and regulation, and the issues involved will never be fully resolved. We are unlikely ever to be satisfied that we have gone as far as possible with routine data sources to meet information needs for planning. This view of the future should not be interpreted as pessimistic, however-it simply recognizes several realities, including the complexity and uncertainties associated with many of the issues in health planning and the implausibility of achieving a state of sufficiency with available data.

In this paper, my approach is to proceed from a

This paper is adapted from one presented at the 18th national Public Health Conference on Records and Statistics, Washington, D.C., August 4, 1980. consideration of the nature of the demand for information to a discussion of routine data sources that have been identified as resources to meet the demand and, finally, to an assessment of the issues to be dealt with in effectively joining demand and capacity.

Health Planning

It is now about 6 years since the enactment of Public Law 93-641, the National Health Planning and Development Act (1), which authorized the establishment through Federal funding of 205 local area health systems agencies (HSAs) and 57 State health planning and development agencies (SHPDAs). What distinguished this legislation from earlier mandates for national planning and from State and local planning efforts by official health agencies and other planning bodies that had been underway for many years were its comprehensiveness, its requirement for setting guidelines that direct the planning effort, and its provision of a defined structure for meeting the goals and objectives.

Klarman (2) captured the significance of Public Law 93-641 as:

The establishment of pervasive, elaborate, and intricately balanced structures of planning joined to regulation; a linkage among federal programs for planning, resource development, and purchase of health care services; a distribution of authority and responsibility between the federal government and the states, between the state governments and local areas, between public employees and advisory groups at the federal and state

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levels, and between governmental auspices and voluntary, nonprofit auspices at the local or areawide level.

It is worth reviewing some aims of the legislation and areas that were later identified for concentrated attention. The HSAs and SHPDAs were charged with responsibility to increase accessibility, acceptability, continuity, and quality of health services provided; improve health status; restrain increases in the cost of providing health services; and prevent unnecessary duplication of health resources. Priorities initially covered primary care services for the underserved, multi-institutional arrangements, developing group practices and HMOs, increasing the supply of physician assistants, advancing health promotion and disease prevention programs, and improving the quality of care. Supply, distribution, organization of health resources, and certificate of need determinations are key elements (3).

Imbedded in all of these objectives is the requirement that the local agency knows what and where the current needs and deficits are and how effective the actions taken are in producing change. A quantitative base is required for making these assessments, and for this purpose, at the local level the dependency is primarily on available sources of data. The expectation is that new attention will be given by others to the production of data and the resolution of problems of content, quality, measurement, and timely availability. The resulting descriptive information is expected to be adequate for many planning and assessment purposes. However, there is often a gap in knowledge about the relationship between structural and process changes being advanced and effects being sought. And, if the stakes are high, nothing short of special research will meet the need for information.

To further the development of available sources, the National Center for Health Statistics (NCHS) was authorized legislatively to develop a Cooperative Health Statistics System, which in 1978 was recognized in statutory form as the CHSS. Other provisions of legislation were designed to strengthen the capacity of the National Center for Health Services Research (NCHSR) in advancing the conduct of research useful for policy and planning purposes and to create a new locus for technology research through the establishment of a National Center for Health Technology. An additional factor is the emergence of the Health Care Financing Administration (HCFA), which has fiscal responsibilities for cost-effective delivery of publicly funded health services, as a strong force in developing available sources of related data and in furthering research. Other Federal agencies, notably the Bureau of Health Professions and the National Institute of Mental Health, as well as voluntary agencies, for example, American Hospital Association, American Medical Association, and American Nurses Association, have been important sources for relevant data.

From the standpoint of health planning agencies some of the potential for contributing to the planning process is being realized; much of it is still a promise. The March 1980 report of a committee of the Institute of Medicine on "Health Planning in the United States, Issues in Guideline Development," makes the following sharp criticisms of the current situation (4):

While the proper development of health planning guidelines is dependent on a firm empirical base, the committee is concerned about the absence of sufficient quantitative information and sound analyses for health planning. Health planning and regulation have been hampered by (a) an inadequate data base (for example, virtually no small area morbidity data or data on hospital discharges); (b) limitations in the applicability of analytic techniques and appropriate research methods (for example, functional classifications for long term care patient placement assessment, and the concept of medical need for individual health problems to estimate the need for services or equipment on an area-wide basis); (c) insufficient knowledge of the efficacy of services or appropriate conditions or circumstances under which services are useful (for example, electronic fetal monitoring, coronary by-pass surgery).

The report also comments that:

The base of data and knowledge about the collection and use of statistics could be expanded in several ways: existing data systems could be sources of data which are routinely shared with planning agencies. This is already occurring with some data from the NCHS, HCFA's Medicare files and the Bureau of Health Manpower's Area Resource File. While this is a step forward, such data are not current and are most useful as benchmarks. Analysis of such data would help to identify problems that would require special studies. Because they are part of national data sets, they produce data on the local area that can be compred with regional, state, and national figures to identify how an area stands in relation to other areas.

These statements appear toward the end of a critical appraisal of past performance and future requirements for the "process of national guidelines development (from agenda development through evaluation and revisions)." They are not elaborated upon to define the issues in planning for which routine data sources by themselves would be relevant and where they would have to be linked to products of special studies or other sources of information. It is not my intention to perform this function but to probe somewhat more fully into the nature of routine data sources and the potential for enhancing their utility in the planning process, avoiding too many overstatements.

Routine Data Sources

There are, of course, guideposts for approaching the contribution of routine data sources. Of great importance is the content, past experience, and possible future direction of the CHSS, which also has been critically reviewed by an independent panel. Another guidepost consists of several developments in recent years that increase the likelihood of routine data sources contributing to planning. To be clear about our frame of reference, routine data sources in the health field are defined as information systems in which data are recorded or collected continuously or periodically for program, legal, operational, or reimbursement reasons. The CHSS designated six components for a broad-based health data system that meet this definition—vital statistics, health facilities, health manpower, hospital care, long-term care, and ambulatory care statistics. A seventh component, the National Health Interview Survey, would be classifiable as "routine" under an extended definition that places heavy emphasis on reasonable assurance of periodic data collection. Potential or realized applications from these data sets cover a variety of interests direct application to health planning under Public Law 93–641 is only one, and that, in many instances, is a relatively recent addition.

The components identify subject areas of prime concern to health planners at all three levels of jurisdiction —Federal, State, and local. Vital statistics represent the single source of information on health status that can be examined over a long period, geographically disaggregated to the county and city levels and down to subareas within a city or aggregated across civil subdivisions for medical market analysis. The vital statistics source in no way detracts from the importance of seeking ways to develop morbidity data and other measures of health status for local areas, as pointed out by the Institute of Medicine Committee.

However, we do not have such information and, in any event, vital statistics are not quite the insensitive measures we often make them out to be. Birth statistics tell us a great deal about adolescent pregnancies; what segments of the population are receiving poorly timed prenatal care; and many of the circumstances related to prematurity. Measures of infant mortality, particularly when derived from matched birth and death records, are still usable, even in our society, as indicators of broad health status, health behavior, and resource problems; this is in addition to what they tell us about the intensity and characteristics of a specific problem. Further, the effects of actions to change the situation can be rapidly determined, a possibility that is not realizable for many other health conditions whether the measure is mortality, morbidity, or functional status.

The ability to examine trends and conduct inter-area comparisons for mortality in childhood and causes of death among adults adds great power to any assessment of where and what type of new resources may be needed. Since mortality from ischemic heart disease and cerebrovascular diseases can be reduced, as evidenced by the downward trends in the past 10 years, the situation in an HSA or subarea where such reductions are not occurring leads to questioning the role of available or new resources. This application can be broadened to

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other causes of death that are indicators of adverse health conditions in specific geographic areas. It requires the resolution of technical problems in the production of information that identifies "hot spots," an issue that is currently being dealt with through a contract from NCHS to a group of investigators at Johns Hopkins School of Hygiene and Public Health, headed by Alan Gittelsohn (5). Among the objectives is the development of efficient computer systems for the surveillance of variations in mortality rates over time and space to identify patterns indicative of emerging health problems. While the original intent was to make available a procedure for national use by NCHS, this methodology and an alternative approach developed by Lerner (6), also at Johns Hopkins, are being applied to the Central Maryland HSA's planning areas and the city of Baltimore's health districts with promising results.

The new set of interests in routine mortality statistics has also led to publication of Statistical Notes for Health Planners by the NCHS (7) and to work aimed at new uses for mortality data bearing directly on planning agencies' responsibilities in the prevention area. The Working Group on Preventable and Manageable Diseases, chaired by Rutstein, has proposed the use of "sentinel events," that is, unusual events-principally causes of deaths that are preventable-as an alert to conditions in a particular area requiring action (8). The methodology being developed by Gittelsohn really represents a next phase, that is, solving practical problems in implementing this concept. In a forthcoming paper, "Towards an Index of Preventable Mortality," Woolsey (9) has some interesting, new approaches to the use of mortality statistics in identifying achievable levels of improvement and a consideration of statistical issues involved that will certainly attract a great deal of attention.

Hospital care statistics, when aggregated for total discharges or on a large sample and when available for analysis by patient origin, represent another highly relevant data source for planning purposes despite the problems in accuracy of reported diagnostic information that have been identified by investigations by the Institute of Medicine (10). The major advances being made in classifying discharges into homogeneous diagnostic categories are providing an assortment of approaches to case mix that are being used with increasing effectiveness by cost review commissions. They also offer a useful tool to planning agencies in assessing variations in utilization and examining alternative ways of meeting need in potentially less costly settings.

There is justifiable impatience with the slow progress in the devlopment of such data for local areas on a nationwide basis. HCFA now has the responsibility for expanding coverage of hospital statistics, but such expansion is not likely to be accomplished quickly. In the meantime, the hospital experience of Medicare beneficiaries, which is part of the ongoing data collection system in HCFA, may possibly provide valid indicators of the use of hospitals by the total population in the community. This routine data source cannot replace a system that covers all age groups when the need is for rates of hospitalization for such procedures as tonsillectomy and adenoidectomy and hysterectomy. But the aim would be to overcome the present inadequate supply of data through broad measures of hospital use by patient origin. The results of exploratory studies of Wennberg and Gittelsohn in relatively small States encourage further examination of possible use of Medicare data on a wider scale (11).

The importance of planning for health facilities and for gathering statistics on health manpower needs no elaboration. The mandate to improve the supply and distribution of health resources and the decision-making authorities given to planning agencies depend on detailed information on facilities and manpower-this extends beyond the institutional sector to ambulatory care. An example of the saliency of this issue is the requirement that HSAs include in their 5-year Health Systems Plans, now in preparation, a detailed examination of the number (and rates per unit population) of primary care physicians required to meet health care demands in their areas. Manpower data generated from routine sources such as licensure systems or periodic surveys suffer from limitations that justify supplementation through special studies; for example, in the case of primary care physicians the lack of data on the movement of users of services across geographic boundaries. But, these restrictions do not obviate the applicability of what is derivable from routine sources for planning purposes.

Interest exists in other types of information that, in the long run, could emerge as important resources for a wide range of health planning and program development functions at the State and local levels. Long-term care and ambulatory health care statistics fall into this category.

With the recent appearance of the first recommendations for a "Long Term Health Care Minimum Data Set," the ground is being laid for creating a new "routine data source" (12). The primary focus of the data set is "on people in the health care system, their problems, and their use of services." Prominent among the general functions or purposes are "public monitoring and regulation of services" and "health planning and policy making." There are compelling reasons for paying a great deal of attention to this area. The sector of the population and the health services system affected has reached substantial proportions and will continue to increase. Alternatives to nursing home care are being tested for their cost effectiveness, and the outlook is that planning agencies increasingly will be faced with the need to make difficult decisions regarding community resources for long-term care. The minimum data set includes a more extensive set of items on health status than the corresponding data sets for hospital and ambulatory care. These items cover measures of physical, social, and psychological function, as well as diagnoses, representing a scope that many of us would not have contemplated as feasible. The arguments for moving this way are strong, but some uncertainties will require examination over several years by the kinds of studies on quality, feasibility, costs, and utility recommended by the panel that prepared the minimum data set.

Ambulatory care statistics have been on the agenda longer than long-term care. The first minimum data set is now about 8 years old, and a new set of recommendations is under review. Many reporting systems are in effect to meet requirements for utilization and cost information in publicly funded programs. However, what is generally contemplated as a need for health planning and program development on a community level goes beyond the capacity of such data sources. Whether this need can or should be satisfied through a repetitive information system that has national coverage will remain debatable until a more compelling reason appears. The recent report of the National Committee on Vital and Health Statistics on Information Needs for National Health Insurance advances 10 principles that provide the rationale and requirements for a routine data system (13). But, we are far from national health insurance, and the need for some data on use of ambulatory care is a pressing matter for planning agencies.

The Public Health Conference on Records and Statistics in 1978 directed attention to the role of health interview surveys in filling the data gap, and several areas have moved in this direction (14). An idea now being explored centers on the derivation of synthetic estimates for small areas from the National HIS. Early results reported at the annual meeting of the American Statistical Association suggest that these estimates are likely to be crude and subject to fairly high relative errors (15). This conclusion comes partly from comparisons with data from a telephone survey of a sample of 2,500 families in Baltimore City and surrounding counties. The survey was modeled on the NHIS questionnaire. A more encouraging result is the demonstration of the feasibility of a relatively low-cost telephone methodology for obtaining information on accessibility, utilization, and health status.

Issues

Clearly, the issue of data needs for health planning and the capacity of the various routine data sources just discussed requires far greater detail at both ends, that is, a more explicit identification of the policy and planning questions faced by planning and regulatory bodies and a more specific assessment of how these questions translate into data requirements. The guides for data usage and sources issued periodically by the Health Resources Administration are designed to perform this function, in part. The Statistical Notes for Health Planners and reports from those close to the scene at the State and local levels also have made important contributions. But, the reality is that we are still fairly early in the development of targets and the application of enforcement tools.

Two complimentary approaches would help the move to a different level. One approach is exemplified by the present Public Health Conference on Records and Statistics and other meetings where those responsible for health policy, planning, regulation, and programs join with methodologists and producers of data. The second approach consists of demonstration, research, and evaluation supported by special funding to advance the state of the art in health planning, including identification of issues and effective application of data. These approaches are not new, but there is an urgent need for a comprehensive reassessment of what, in light of experience, we know about planning needs, the effectiveness of available routine sourcs of data, and the technical and analytic issues in bringing together the data elements from several sources of information. Working material could include the HRA's Area Resource File, which has easily accessible user tapes (16). The timing of such an activity for the near future is particularly appropriate because of the availability within the next 6-12 months of population statistics for small areas from the 1980 decennial census. From a longer term standpoint, it is disappointing that the efforts by many interest groups, including those in the health sector, to assure a mid-decade census face defeat because of a congressional decision to not provide funds for planning a 1985 mid-decade census.

Despite the importance of the process of reassessment and resulting guidelines, it will be effective only to the extent that it is linked to resources (personnel and funds) and mechanisms within the States and at the national level directed at multiple functions of health statistics. The dominant factor here is the Cooperative Health Statistics System, which is reinforced by the recent report of a panel, established by the Assistant Secretary for Health, to evaluate the CHSS in light of experience over the past 10 years and to assess changes directed by the health planning, professional standards review organization, and manpower legislation of the 1970s (17).

The observations and recommendations of the panel are both broad and specific. They cover the uneven development of key components in the CHSS, except vital statistics; the problems of quality and lags in availability of data; the shifts in location within the Department of Health and Human Services of responsibility for several components; and the decision criteria that should guide priority setting for selecting components to be included in a joint Federal-State collection system. For present purposes, the following broad conclusions of the panel are most relevant:

The CHSS should be perceived as a nationwide cooperative network of public and private agencies linked together to meet their respective needs for health statistics. The network has a central coordinating agency in each State (the State CHSS Agency) and at the National level (NCHS), but many agencies at every level are active or potential members of the network, either contributing to the production of certain health data or in using these data, or both.

A distinction is made between CHSS—a mixture of public and private interests having largely a State-level orientation—and a Federal program—the Cooperative Health Statistics Program—in which the States participate and the CHSP is the vector for support to the States:

The CHSP coordinates the flow of national data into and out of the system; provides Federal support for State CHSS agencies; takes the lead in developing and updating minimum data sets; and provides professional and technical assistance in statistical methods, data handling, and data use. Management of Federal participation is delegated to NCHS with collaboration of other Federal agencies.

A major conclusion of the panel's report is that because many Federal programs as well as State health programs increasingly require a strong State capacity, a first priority of the CHSP is to strengthen the ability of the States to identify health data needs, to develop appropriate collection mechanisms, and to build the capacity for analysis and use of health data. No activity for which the call for building State capability in health statistics is more pertinent than health planning under Public Law 93-641.

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