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The Cooperative Health Statistics System: Its Mission and Program

**Final Report from the
Task Force on Definitions
to the
Cooperative Health Statistics Advisory Committee
August 30, 1976**

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NATIONAL CENTER FOR HEALTH STATISTICS

DOROTHY P. RICE, *Director*

ROBERT A. ISRAEL, *Deputy Director*

JACOB J. FELDMAN, Ph.D., *Associate Director for Analysis*

GAIL F. FISHER, *Associate Director for the Cooperative Health Statistics System*

ELIJAH L. WHITE, *Associate Director for Data Systems*

JAMES T. BAIRD, Ph.D., *Acting Associate Director for International Statistics*

ROBERT C. HUBER, *Associate Director for Management*

MONROE G. SIRKEN, Ph.D., *Associate Director for Mathematical Statistics*

PETER L. HURLEY, *Associate Director for Operations*

JAMES M. ROBEY, Ph.D., *Associate Director for Program Development*

PAUL E. LEAVERTON, Ph.D., *Associate Director for Research*

ALICE HAYWOOD, *Information Officer*

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COOPERATIVE HEALTH STATISTICS ADVISORY COMMITTEE

CHAIRPERSON

Dorothy P. Rice
 Director, National Center for Health Statistics
 Health Resources Administration
 5600 Fishers Lane
 Rockville, Maryland 20857

EXECUTIVE SECRETARY

Gail F. Fisher
 Associate Director for the Cooperative Health
 Statistics System
 National Center for Health Statistics
 Health Resources Administration
 5600 Fishers Lane
 Rockville, Maryland 20857

MEMBERS

Anita K. Bahn, M.D. 1977
 Professor of Community Medicine
 University of Pennsylvania School of Medicine
 36th and Hamilton Walk
 Philadelphia, Pennsylvania 19174

James L. Dallas 1979
 Chief, Office of Health Resources Development
 Airdustrial Park
 Mail Stop 14-1
 Olympia, Washington 98501

Donald J. Davids 1980
 Chief, Records and Statistics Section and State
 Registrar
 State Department of Health
 4210 East 11th Avenue
 Denver, Colorado 80220

Paul M. Densen, Sc.D. 1978
 Director, Center for Community Health and
 Medical Care
 Harvard Medical School
 643 Huntington Avenue
 Boston, Massachusetts 02115

Clifton O. Dummett, D.D.S. 1979
 Professor and Chairman, Department of
 Community Oral Health and Preventive
 Dentistry
 University of Southern California
 Los Angeles, California 90007

Frank E. Ellis, M.D. 1978
 Regional Health Administrator
 Public Health Service
 Region V
 300 South Wacker Drive
 Chicago, Illinois 60606

Eugene W. Fowinkle, M.D. 1977
 Commissioner, Tennessee Department of Public
 Health
 Cordell Hull Building
 Nashville, Tennessee 37219

Symond R. Gottlieb 1980
 Executive Director, Greater Detroit Area
 Hospital Council, Inc.
 1900 Book Building
 Detroit, Michigan 48226

Lillian Guralnick 1980
 Statistician, Dade-Monroe Professional
 Standards Review Organization
 2701 South Bayshore Drive
 Miami, Florida 33133

Philip M. Hauser, Ph.D. 1978
 Professor of Sociology and Director, Research
 Center
 University of Chicago
 Chicago, Illinois 60637

Lachlan L. Hyatt Chairman, S.C. Governor's Health Policy and Planning Council Edgar A. Brown Building Room 413 Columbia, South Carolina 29201	1977	Aleda V. Roth Director of Statistics American Nursing Association 2420 Pershing Road Kansas City, Missouri 64108	1980
Vito M. Logrillo Director, Health Statistics N.Y. State Department of Health Empire State Plaza Tower Building, Room 303 Albany, New York 12237	1977	Margaret D. West Route 8, Box 48 Annapolis, Maryland 21401	1978
Mildred Mitchell-Bateman, M.D. Director, Department of Mental Health State Capitol Building Charleston, West Virginia 25305	1977	Martha R. Wilson, M.D. Chief, Office of Program Development Alaska Area Native Health Service 3rd and Gambell P.O. Box 7-741 Anchorage, Alaska 99501	1979
Beverlee A. Myers Lecturer, Department of Medical Care Organization School of Public Health University of Michigan Ann Arbor, Michigan 48104	1978	Karl D. Yordy Senior Program Officer Institute of Medicine National Academy of Sciences 2102 Constitution Avenue Washington, D.C. 20418	1979

COOPERATIVE HEALTH STATISTICS ADVISORY COMMITTEE

Task Force on Definitions

MEMBERS

James L. Dallas
Chief, Office of Health Resources Development
Department of Health and Social Services
Airdustrial Park, Mail Stop 14-1
Olympia, Washington 98501

Margaret D. West
Route 8, Box 48
Annapolis, Maryland 21401

Lachlan L. Hyatt
Chairman, South Carolina Governor's Health
Policy and Planning Council
Edgar A. Brown Building, Room 413
Columbia, South Carolina 29201

Karl D. Yordy
Senior Program Officer, Institute of Medicine
National Academy of Sciences
2102 Constitution Avenue
Washington, D.C. 20418

RESOURCE STAFF

Gail F. Fisher
Associate Director, Cooperative Health Statistics
System
National Center for Health Statistics
5600 Fishers Lane
Rockville, Maryland 20857

James M. Robey, Ph.D.
Associate Director, Program Development
National Center for Health Statistics
5600 Fishers Lane
Rockville, Maryland 20857

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THE COOPERATIVE HEALTH STATISTICS SYSTEM: ITS MISSION AND PROGRAM

INTRODUCTION

To plan and develop better health services, to deliver those services in an effective and equitable manner, and to measure their effectiveness requires data on health status and trends, on the availability and utilization of health manpower, facilities and other resources, and on the costs of health services.

Inadequate information in these areas causes major problems for data users. Data on resources and services lack uniformity, continuity, compatibility, and geographic detail. There are wide gaps in coverage. At the same time there is another serious problem. Multiple users of particular types of information are overwhelming individual practitioners and institutions with independent and duplicate demands for data.

To meet problems such as these, Public Law 93-353 authorized the National Center for Health Statistics to develop a cooperative health statistics system "to assist State and local health agencies and Federal agencies involved in matters relating to health, in the design and implementation of a cooperative system." The purpose of this legislation is to establish and maintain a coordinated and uniform data system to guide decisionmaking regarding health care in the United States, to enable them to make timely identification of health needs, to make better planning possible, and to allow more effective monitoring and evaluation of health programs and services. This will permit the health needs of the people to be met more adequately.

LEGISLATION

The Cooperative Health Statistics System operates under the specific legislative authority

of the Health Services Research, Health Statistics, and Medical Libraries Act of 1974 (Public Law 93-353). The uses and purposes of the Cooperative Health Statistics System are further specified in the National Health Planning and Resources Development Act of 1974 (Public Law 93-641)—an example of how emerging programs are using a "data center" concept. Similarly, though less specifically, Professional Standards Review Organization legislation (Public Law 92-603, Section 249(f)) encourages the use of available data.

Public Law 93-353

The Health Services Research, Health Statistics, and Medical Libraries Act of 1974 (Public Law 93-353) authorizes the establishment and operation of the National Center for Health Statistics (NCHS). Establishing by statute what had been established administratively for several years, the law directs the Secretary of the Department of Health, Education, and Welfare to carry out specific functions through NCHS.

Section 306(a) authorizes the Center to collect statistics on

- "(A) the extent and nature of illness and disability of the population of the United States
- "(B) the impact of the 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 . . . and other health institutions,

“(F) utilization of health care . . . ,

“(G) health care costs and financing . . . ,

“(H) family formation, growth, and dissolution.”

Section 306(d) of the law directs the Secretary, through NCHS, to “provide adequate technical assistance to assist State and local jurisdictions in the development of model laws dealing with issues of confidentiality and comparability of data.”

Section 306(e) states that the National Center for Health Statistics will provide five services for the Secretary. They are to

- (1) assist State and local health agencies, and Federal agencies involved in matters relating to health, in the design and implementation of a cooperative system for producing comparable and uniform health information and statistics at the Federal, State, and local levels;
- (2) coordinate the activities of such Federal agencies respecting the design and implementation of such cooperative system;
- (3) undertake and support (by grant or contract) research, development, demonstrations, and evaluations respecting such cooperative system;
- (4) provide the Federal share of the data collection costs under such system; and
- (5) review statistical activities of the Department of Health, Education, and Welfare to assure that they are consistent with such cooperative system.

Section 306(f) directs NCHS to “cooperate and consult with (other) Federal departments or agencies and with State and local health departments and agencies, (and) to utilize, insofar as possible, the services or facilities of any agency of the Federal Government . . . of any appropriate State or other public agency and . . . of any

private agency, organization, group, or individual, in accordance with written agreements between the head of such agency, organization, or group and the Secretary . . . (and with payment), if any, in such amounts as may be provided in such agreement.”

Public Law 93-641

The National Health Planning and Resources Development Act of 1974 (Public Law 93-641) authorizes the establishment and operation of health planning agencies at the local level (health systems agencies) and at the State level (State health planning and development agencies).

Section 1511, Part B—Health Systems Agencies—establishes health service areas, each having a geographic region appropriate for the effective planning and development of health services.

Under Section 1512, the Secretary of the Department of Health, Education, and Welfare is directed to establish a health systems agency for each health service area. These agencies may be a nonprofit private corporation, a public regional planning body, or a unit of a general local government. The purpose of these health systems agencies is to improve the health of residents in their areas by increasing the accessibility, acceptability, continuity, and quality of health services while restraining increases in the cost of health services and preventing unnecessary duplication of health resources.

To meet these responsibilities, the health systems agencies are directed to assemble and analyze data concerning:

- “A. the status (and its determinants) of the health of the residents of its health service area,
- “B. the status of the health care delivery system in the area and the use of that system by the residents of the area,
- “C. the effect of the health delivery system on the health of the residents of the area,
- “D. the number, type, and location of the area’s health resources, including health services, manpower, and facilities,

“E. the patterns of utilization of the area’s health resources, and

“F. the environmental and occupational exposure factors affecting immediate and long-term health conditions.”

The need for health planning agencies to utilize an existing mechanism for data collection and analysis rather than using their limited resources to duplicate a current system resulted in the regulation that health systems agencies coordinate their activities with the cooperative system provided for under Section 306(e) of Public Law 93-353. These agencies are also directed to refrain from undertaking the collection of data where adequate data are already collected by other entities—including those in the Cooperative System provided for under Section 306(e). When a health systems agency wishes to undertake the design, development, and operation of a new data system, whether directly or indirectly by using contractors or consultants, it must obtain the prior approval of the Secretary. Before making a decision, however, the Secretary must consult with the State-wide Health Coordinating Council, if any, for each State in which the agency’s health service area is located.

In carrying out its responsibilities, the State planning agency *must*

Provide for the coordination (in accordance with the regulations of the Secretary) with the cooperative system provided for under Section 306(e) of the activities of the State Agency for collection, retrieval, analysis, reporting, and publication of statistical and other information related to health care. (Section 1522 (a), (7), (A))

Part C—State Health Planning and Development—provides for the designation of State health planning and development agencies. Their functions include

conducting the health planning activities of the State, including development of State plans to assist in the review of the State medical facilities plan,

making findings on the need for new institutional health services, and

determining the appropriateness of the services being offered.

USERS OF THE SYSTEM

Users of the Cooperative Health Statistics System include a wide range of public and private agencies, organizations, and individuals concerned with or involved in the planning, provision, regulation, or evaluation of health services and health resources at the national, State, and local levels.

Federal users of the data generated by the Cooperative System include the Health Resources Administration, National Institutes of Health, Alcohol, Drug Abuse, and Mental Health Administration, Social Security Administration, Health Services Administration, Center for Disease Control, U.S. Bureau of the Census, other agencies, and the Congress. The roles of some of these users will be noted in following pages.

Official State and local agency data users include those concerned with the direct provision of care, with planning, and with licensing, rate-setting, certificate of need, and other regulatory activities, as well as those concerned with population growth and change. These agencies include health, welfare, and human resources departments, State planning agencies and health systems agencies, third-party payers, fiscal intermediaries, professional standards review organizations, departments of education, higher education councils, and employment services.

Professional organizations—particularly those concerned with the health professions and health facilities and health researchers—also use the Cooperative Health Statistics System.

DATA NEEDS AND SOURCES

Needs

“Health statistics production in this country presents a picture of uncoordinated data collection, aggregation, presentation and analysis among various Federal, State, local, and non-governmental sources. The separate efforts underway are frequently duplicative of one another and despite common goals, possess little

of the continuity, compatibility and standardization which are essential to a reliable health statistics system

"This situation will be intensified by the increasing number of new Federal programs planned or in operation for quality assurance, cost control, resource planning, health insurance, and service delivery systems

"The need for formal mechanisms for reaching basic decisions regarding cooperative efforts between agencies in the development and support of statistical systems is clearly indicated."¹

Needs for health data range from patient management decisions to the establishment of national health policy. To meet these needs of its users, the Cooperative Health Statistics System should be able to provide current national, State, and local data that have uniform definitions in the areas of

Health status,

Resources of health manpower, facilities, and services,

Utilization of health services and facilities,

Expenditures and sources of funds for health services and for the development of health resources, and

Environmental, social, and other health hazards.

Data available for these areas are widely varied in coverage, completeness, uniformity, and usefulness. They are available, if at all, in piecemeal fashion, from a variety of sources.

The Cooperative Health Statistics System, seeking to identify data components which can provide a considerable part of the needed information, has cooperated with producers and users of data to develop minimum essential data sets for certain components.

Responding to the growing public responsibilities related to the planning, provision, and evaluation of health services, the Assistant Secretary for Health has established a Health Data Policy Committee. Composed of representatives

from the Public Health Service agencies, the Social Security Administration, and the Social and Rehabilitation Service, the Committee advises him on important policy issues concerning the collection and analysis of health and health-related statistics throughout the Department, and assists him in coordinating the Department's health data requirement. In this capacity, the Committee has prepared a Health Statistics Plan² which reviews the present situation on health statistics production, identifies the Department's current health statistics activities, and identifies some of the major gaps. It found that

"The existing general purpose health-related statistics programs of the Department of Health, Education, and Welfare, despite the high quality of many of the individual segments, as a whole are inadequate"

Putting stress on the problem of geographic specificity of data, the Committee said that

The most significant challenge in the field of health statistics is the development of data systems that are capable of satisfying the multiple needs for data at the regional, State, and local levels and other geographic aggregations, and that provide the types of data needed for evaluation of the impact of major Federal health programs.

Reliable, timely, pertinent, and comparable health data and analysis are needed at all levels which will describe the health status of the population, the availability of resources, the accessibility of services, the costs of services and resources, the sources of funding, the utilization of present services, and the quality of care. Without such statistics, the capacity at every level of the health industry to plan, manage, and evaluate our tremendous investment in health resources and delivery systems is severely limited.

Existing general purpose data systems do not, in general, provide data in enough geographic detail to be of maximum use to even the Federal level consumers, much less the State and local users.

¹Department of Health, Education, and Welfare: *Health Statistics Plan. Fiscal Years 1976-1977*. Public Health Service. Washington. U.S. Government Printing Office. Nov. 1975.

²Ibid.

Sources

Data on health status, resources, and services come from a wide variety of sources. For some areas the sources are excellent; for others they are multiple but still inadequate. For still others, there is virtually no way to get usable information.

Basic to all health and health services data is information on the size, character, and growth of the population. This comes from decennial and supplemental censuses conducted by the U.S. Bureau of the Census and from birth, death, marriage, and divorce records. The collection, analysis, and publication of vital statistics from the latter has long been a responsibility of the States and of the National Center for Health Statistics. Birth and death data are now collected routinely, with standardized basic data sets, by all States, and are transmitted to the National Center for Health Statistics for further processing, analysis, and publication. Although there is still need for improvement, reasonably current data from this Cooperative System component are available for the Nation, for most States, and for many smaller geographic areas. This is the element of greatest coverage and accuracy in the Cooperative System.

Health status.—Information on health status is derived from birth and death reports and from a variety of other sources which provide information on, or clues to, some aspect of health status. The most comprehensive information on health status comes from the Health and Nutrition Examination Survey of the National Center for Health Statistics. This provides national and regional data but is too complex and expensive for routine use at a State or local level.

For some years the National Center for Health Statistics has also conducted the Health Interview Survey—a periodic sample survey providing national and regional estimates for a variety of measures of disability and of utilization of health services. Valuable as these surveys are, they have inherent limitations since they provide only indirect indicators of health status such as conditions, disabilities, and impairments as perceived by the individual or by a family member.

To increase the usefulness of the Health Interview Survey to the States and to smaller

geographic areas, there are now plans to redesign the sample and quadruple its size. Within several years this should include 160,000 households, making possible estimates of health status and health service utilization for smaller areas. At the same time, it will allow selective sample size increases for States desiring to fund more detailed surveys. Technical assistance will be provided to State and local areas wishing to collect such data from households.

Health manpower.—Sources of health manpower data include both public agencies, particularly the States in carrying out their licensure and other regulatory responsibilities, and private agencies and organizations representing individual health professions. Professional organizations such as those of physicians, dentists, and nurses collect and publish national and State inventory data covering members of their professions. However, data from these sources range widely in completeness and in comparability. Definitions, even of the persons included in total counts, are not uniform or precise. There is also little information available about the rapidly proliferating new health occupations.

Under the Cooperative System, more detailed statistics are now being collected for 13 occupations. The National Center for Health Statistics, for instance, compiled considerable national and State data on the numbers, distribution, and characteristics of members of many health professions and is publishing this information in an annual publication.

Health facilities.—The situation of facility statistics is similar to health manpower statistics since State public agencies develop data in connection with licensing, certificate of need, and other responsibilities, while the American Hospital Association and State and local hospital associations also collect and publish data to meet their various needs.

To eliminate some of this duplication, the American Hospital Association and the National Center for Health Statistics began, in 1968, to pool their resources. The result is the yearly publication of the Annual Survey of Hospitals. Today the American Hospital Association, with NCHS support, surveys their registered hospitals, while other institutions are surveyed by the Center. NCHS also maintains a Master Facilities Inventory which includes not only hospitals but also nursing homes and other inpatient health

facilities. Data on mental hospitals and other mental health facilities, collected jointly by the National Institute of Mental Health and NCHS, are also incorporated in the Master Facilities Inventory.

Inadequacies of the data now available include incomplete coverage of all types of facilities (specifically outpatient facilities), inadequate classification of facilities, and inadequate data on funding and staffing.

Inpatient care.—For some years the National Center for Health Statistics has conducted the Hospital Discharge Study, a national sample survey on hospital utilization. Other data collection efforts now under way include those related to Medicare, Medicaid, professional standards review organizations, and private organizations such as the Commission on Professional Hospital Activities. Data on the utilization of mental hospitals are collected routinely by the National Institute of Mental Health. Of all these efforts, only the NCHS Hospital Discharge Study provides a national picture. The other data collection efforts, serving a particular purpose with respect to selected patients (such as Medicare) or institutions (such as the Commission on Professional and Hospital Activities), cannot meet the needs of public agencies looking for an understanding of the total hospital care situation. Under the Cooperative Health Statistics System, developmental projects are funded in selected States to obtain hospital care data representative of the services provided to the total population.

Much worse is the data available on services provided by nursing homes and other extended care facilities. The National Center for Health Statistics has collected nursing home facility and patient data on a periodic basis, but the analysis is mainly for national purposes and has limited use on a State or local level.

Ambulatory care.—Data on care given in physicians' offices, group practice settings, public health clinics, hospital emergency room and outpatient services, and telephone consultations are similarly limited. The National Center for Health Statistics now conducts the National Ambulatory Medical Care Survey which provides national data on some of these ambulatory care elements. Expansion of this survey to meet State purposes is being tested.

Expenditures, costs, prices, and financing.—

There is need for better national, State, and regional information on total expenditures and on sources of financing in relation to family composition, socioeconomic characteristics, and insurance coverage. This is probably the area for which the greatest interest exists today, and the one for which available data sources are the least adequate. Data are needed not only for costs and prices of services provided by traditional methods and under traditional systems but also on the newer types of health service organizations such as group practices and health maintenance organizations, particularly on costs of services in relation to organization, utilization, staffing, and methods of payment and financing. There is almost no information on costs of treatment and costs of hospitalization in relation to diagnosis and outcome.

Data to meet these needs must be assembled from many sources, including the recipients of services (through such mechanisms as the Health Interview Survey), from institutions providing care, from noninstitutional providers, and from third-party payers.

Environmental, social, and other health hazards.—The past few decades have witnessed great changes in the physical and chemical contaminants of man's environment and an increasing recognition of the impact of both the physical and social environment on the health of man. Consultants to the United States National Committee on Vital and Health Statistics have been asked to prepare recommendations about statistical data bearing on health effects of the environment which should be collected, ways in which they should be collected, and changes which should be made in existing measures of environmental factors in order to better relate environmental factors to the health effects.

Although present sources are inadequate in providing needed data, there are sources now available which could be used more fully and effectively. These include:

Death reports—data on occupation and on cause of death, including cancer by site, respiratory disease, heart disease, accidental death;

Hospital discharge data; and

Health Interview Survey and Health and Nutrition Examination Survey—data on acci-

dents, injuries, nutritional status, and other characteristics.

COOPERATIVE HEALTH STATISTICS SYSTEM

In response to the need for more adequate health-related data to meet national, State, and local needs, the National Center for Health Statistics, in 1970, began work looking to the establishment of a Cooperative Health Statistics System. Since that time needs have been identified with more precision; high-priority data components have been identified; certain data sets have been established; and the Cooperative System is now being placed in operation with the cooperation of public health and statistical agencies, professional groups, and other private organizations.

Vital statistics data, provided by the States to the National Center for Health Statistics, are now a basic component of the Cooperative System. As NCHS decentralizes responsibility for collecting data on health manpower and facilities from the Federal to the State level, the States' role in the Cooperative System will increase proportionately. In the area of utilization data—particularly hospital discharge data—the change from a national sample to State and local level collection is more difficult. For certain other data areas, there is the possibility that methods developed in national sample surveys will be expanded and translated into a State setting.

There are, however, certain data collection efforts of the National Center for Health Statistics which do not lend themselves, because of their complexity and cost, to such decentralization. The Health and Nutrition Examination Survey and the Health Interview Survey, for instance, must continue as direct national efforts, although the Health Interview Survey protocols can be used on an *ad hoc* basis to meet needs in some States and large metropolitan areas.

Cooperative System Characteristics

When fully developed the System will have the following characteristics:

It will provide national, State, and local agencies and organizations with comparable

data on vital events, health manpower and facilities, utilization and financing of health services, and related elements.

It will play the lead role in coordinating national, State, and local health data systems, to the end that there will be maximum comparability, completeness, accuracy, and timeliness and that unnecessary duplication will be eliminated.

It will be the primary mechanism by which the Federal Government closes the gap in its health statistics system and seeks to avoid duplication.

It will meet the data needs of a wide range of users of health data and will provide analytical and technical assistance to make the data useful.

It will preserve the required and proper confidentiality of data in shared systems.

It will be responsible for providing mechanisms for collecting quality data in requisite geographical detail. Data collection will conform to a set of minimum requirements adopted by the Department of Health, Education, and Welfare after consultation with State and local governments and health organizations in the private sector. These requirements will include use of minimum data sets and uniform definitions, classifications, and quality standards.

It will carry a continuing responsibility for research and study of health data needs and for developing methods and mechanisms to meet such needs.

It will have, in each State, a health statistics center or focus that is a public agency or a nongovernmental entity officially designated by the governor or the appropriate State public agency or official in agreement with the National Center for Health Statistics and with major producers of the data.

It will have, in each State center, the capacity for data analysis and will prepare and disseminate analyses on a regular and timely basis.

It will have funds for the maintenance of the System, which are provided by the members

of the cooperators with the System, on a fair-share cost basis.

Program Development

In 1971, research and development leading to the establishment of the Cooperative System was initiated by the National Center for Health Statistics in cooperation with the National Center for Health Services Research. First steps included examining alternatives for content, structure, and methods. This examination identified data elements of highest priority and sought to develop the highest possible level of compatibility in data handling techniques with similar activities in other parts of the Department, the U.S. Bureau of the Census, and other agencies. From this work emerged comparable definitions, standards, and procedures for the collection, processing, analysis, and presentation of data. Close-working relationships with national and State agencies, and with other data producers and users, also emerged as the Cooperative System was developed.

Established Need for Data Coordination

The great increase in the concern of the Federal Government with respect to the planning, provision, and assessment of health resources and health services has called for a corresponding need for and collection of health-related data. Federal concern, financial support, and data collection efforts related to the supply of health facilities and health manpower go back for many years, particularly in relation to the Hill-Burton hospital construction legislation and to the series of health manpower resources laws. Legislation supporting Medicare, Medicaid, and maternal and child health services has also given the Federal Government a major role in paying for health services and responsibility for assessing that care. The new health planning legislation has broadened and reinforced these Federal concerns.

The effects of these Federal responsibilities have resulted in a sharp growth in needs for data to plan, administer, and evaluate health service and health resource programs and a proliferation of often duplicated reporting requirements with

consequent burdens on State agencies and on health service institutions.

As a result of the problems arising from this proliferation, the Department's Health Data Policy Committee has decided that the Cooperative Health Statistics System will play the lead role in coordinating Federal, State, and local health data systems. A number of mechanisms have been developed to enable the System to meet such responsibilities.

Coordination and Decisionmaking

The Cooperative Health Statistics System is being developed under a policy of maximum participation in decisionmaking by data producers and users. The mechanisms include use of advisory committees, formal and informal agreements, and working arrangements with other Federal agencies, with State and local agencies, and with professional organizations.

Advisory committees.—One of these mechanisms, the Cooperative Health Statistics Advisory Committee, was established in 1974 by the Secretary of the Department of Health, Education, and Welfare to advise, consult with, and make recommendations to the Secretary and to the Director of NCHS on general program policy and plans for research, development, and implementation of the Cooperative Health Statistics System. In this capacity, the Advisory Committee assures that national, State, and local agencies are appropriately involved in the Cooperative System and develops appropriate uniform standards on the content, definitions, data sets, and methodology used by the Cooperative System. The Committee also oversees the review, endorsement, and promulgation of national standard data sets in the areas of hospital, ambulatory, and long-term health care; the effective and efficient operation of the System; and the recommendation of temporary Technical Consultant Panels to investigate assigned technical problems.

Members of the Committee include the Director of the National Center for Health Statistics, who serves as Chairman, and 18 members appointed by the Chairman. Members are nationally recognized scientists such as demographers, biostatisticians, sociologists, economists, and political scientists. They are

selected for their competence, interest, and perspective in the area of health care delivery system data needs. Other providers and users of health data are also on the Committee. They include executives of State and local health departments, leaders in local health planning agencies, representatives of interested national organizations, and leaders in other Federal statistical agencies.

Another decisionmaking mechanism, the United States National Committee on Vital and Health Statistics, has authority, under Public Law 93-353, to assist and advise the Secretary of the Department of Health, Education, and Welfare on matters related to the National Center for Health Statistics. This Committee coordinates statistical data activities within the Department and establishes and updates minimum data sets. The Committee has also established Technical Consultant Panels to develop recommendations on such data sets for action by the Committee.

Data coordination among Federal agencies.— In accordance with the requirement of Public Law 93-641, the National Center for Health Statistics and the Bureau of Health Planning and Resources Development have reached an agreement on implementation of health data activities. This includes provisions for

- Definition of data needs and standards development,

- Operational responsibility and maintenance of quality control,

- Technical assistance and training, and

- Research and development in data utilization.

This agreement emphasizes the primary responsibility of the National Center for Health Statistics and assigns managerial authority for statistical activities to the Center.

The Federal and State governments as well as other agencies need hospital utilization data on the total population serviced, including specific data on patients for whom Federal payments funds are used. These statistics help ascertain the proficiency of patient management, program management, evaluation, and research programs.

However, the development of cooperative relationships and procedures with common access to hospital discharge data is hampered by many problems arising from the confidential nature of the records, because of the need for speed in meeting the needs of some of the users, and because of the multiple vested interests in these data.

Its professional standards review organizations make the Social Security Administration one of the most important agencies in need of these discharge records. Authorized in 1972 under the Social Security Administration amendments, these organizations involve practicing physicians in the review and evaluation of health care services covered under the Medicare, Medicaid, and maternal and child health programs. They are responsible for assuring that health care paid for under these programs is medically necessary and consistent with professionally recognized standards of care and with encouraging use of less costly sites and modes of treatment where medically appropriate. The professional standards review organizations are required to collect discharge data on their covered patients and to review services furnished in and by hospitals and other health care institutions. They may also review other types of health care, such as ambulatory and long-term care.

The Social Security Administration is also a major source of data on health expenditures at the national and State level. The Cooperative Health Statistics System, in cooperation with the Social Security Administration and the Health Services Administration's Bureau of Quality Assurance, is developing data systems which will respond to utilization of services information.

For many years the Public Health Service has also been concerned with the nation's supply of and need for health manpower. There have been a variety of cooperative and contractual relationships with professional organizations and other agencies to secure health manpower data necessary in seeking solutions. Increasingly, however, the Federal responsibility is focusing on the Health Resource Administration's Bureau of Health Manpower and National Center for Health Statistics, who work closely with health

professions organizations. Agreements with these organizations have taken a number of forms, including the purchase of data tapes and contractual relationships for the conduct of health manpower inventories. For several of these professions, NCHS has also conducted surveys to establish or update professional inventories. In November 1974, the responsibility for obtaining information on the current supply of health manpower through national inventories was transferred from the Bureau of Health Manpower to the National Center for Health Statistics.

Paralleling these efforts in the past few years has been the development and implementation of the manpower statistics component of the Cooperative Health Statistics System. The States' increased need for such data resulted in the Cooperative System being given the primary Public Health Service responsibility. Agreements have been reached that lean toward establishing uniform data content, definitions and standards, and making the States the primary data collectors. There are now 13 health occupations for which the participating States are collecting and processing data for the Cooperative System. These are doctors of medicine, doctors of osteopathy, dentists, pharmacists, optometrists, registered nurses, licensed practical nurses, dental hygienists, physical therapists, nursing home administrators, chiropractors, podiatrists, and veterinarians.

In addition to these health manpower statistics, State and local government agencies, through their mental health organizations, have an increasing need for statistical data to facilitate patient care, utilization review, program planning, budgeting, and monitoring and evaluation. The Health Planning Act and the Community Mental Health Centers Act are also increasing the demand for such data.

In response to these needs, the Alcohol, Drug Abuse, and Mental Health Administration Statistical Plan has proposed a Mental Health Statistics Improvement Program for their National Institute of Mental Health. If utilized, this program would bring State and local mental health agencies up to a minimum standard level of statistical reporting to meet both the needs for program management and the baseline

statistics requirements of the Cooperative System. A National Institute of Mental Health and National Center for Health Statistics Coordinating Group has been established to develop a plan and to identify areas in which the two organizations can work together through the Cooperative Health Statistics System.

In addition to health manpower and mental health statistics, data are also needed on nationally notifiable diseases and immunizations. The Center for Disease Control (CDC), responsible for controlling infectious and other preventable diseases and conditions, collects and publishes data on these diseases and immunizations and conducts surveillance of infectious diseases, other preventable conditions such as vector-borne and dental diseases, occupational health and safety problems and certain environmentally induced health problems—on a national level as well as for subareas. These data comprise the only uniform statistics on morbidity available at the local level for all jurisdictions in the Nation.

Until recently, national statistics on legal abortions were collected by the Center for Disease Control and published in an annual Abortion Surveillance Report. In 1974, 51 States and the District of Columbia provided partial or complete information. It was agreed by the Center for Disease Control and the National Center for Health Statistics that reporting of national baseline abortion statistics is logically the responsibility of the National Center for Health Statistics. The States should begin reporting such data to NCHS rather than to CDC as soon as they are able to meet the reporting standards established by NCHS.

The National Center for Health Statistics has developed reporting standards for legal abortions. States meeting these standards are reporting to the National Center for Health Statistics as part of the vital statistics component of the Cooperative Health Statistics System. As the level of performance for a particular State meets the National Center for Health Statistics standards, reports formerly made available to the Center for Disease Control will be transferred to NCHS.

Data components.—Seven data areas were originally identified as necessary components of

the Cooperative Health Statistics System. They are vital statistics, health manpower statistics, health facilities statistics, hospital care statistics, long-term care statistics, ambulatory care statistics, and health interview statistics. Work was subsequently undertaken to establish minimum essential data sets for these areas, with four areas—vital statistics, health manpower statistics, health facilities statistics, and hospital care statistics—selected for first priority.

Research and development grants were made to develop procedures and to test data sets in these components. Mechanisms used include

Advisory and technical committees, including the Technical Consultant Panels established by the United States National Committee on Vital and Health Statistics.

Ad hoc task forces to develop and evaluate initial data sets.

Pilot testing.

Potential data producers and users review and comment, and national and regional workshops.

Data sets for one of the seven data components—vital statistics—have been established for some time and are revised over a cycle of 8 to 10 years. To meet their legal responsibilities, States routinely collect information on birth, death, marriage, and divorce statistics and have for many years provided NCHS with microfilm copies of birth and death certificates, and for most States marriage and divorce records. States funded under the vital statistics component of the Cooperative System provide these data to the Center on tapes according to uniform standards. Another data activity in this component—abortion reporting—will soon be initiated in a few States. The vital statistics system, with its close working relationships between the States and the National Center for Health Statistics, has served as a model for the Cooperative System.

Another of the data components—manpower statistics—focuses on obtaining basic information on the numbers, characteristics, and geographic distribution of health manpower in the 13 health occupations licensed in all or

nearly all States and to furnish a frame for special surveys. A uniform minimum data set for all occupations was developed by the National Center for Health Statistics in consultation with other producers and users of health manpower data. As experience is gained in applying this uniform minimum data set, it will be reviewed and modified for specific information needs about each occupation.

The first stage of development by the participating States established rosters of at least 7 of the 13 occupations licensed in 49 or more States. These occupations are chiropractors, dental hygienists, dentists, doctors of medicine and osteopathy, registered nurses, licensed practical or vocational nurses, nursing home administrators, optometrists, pharmacists, physical therapists, podiatrists, and veterinarians.

The second stage instituted surveys connected to the State licensure renewal procedure, utilizing the minimum data set. A future expansion will extend coverage to all health manpower, both licensed and unlicensed. The National Center for Health Statistics will be responsible for unduplicating, for the States, persons licensed in more than one State.

Minimum data sets on a third data component—statistics on hospitals, nursing homes, and other inpatient facilities—have been developed by NCHS. These sets, which closely parallel those used to collect national data for the Master Facility Inventory, will be reviewed periodically by the United States National Committee on Vital and Health Statistics. Participating States usually obtain this data through State licensing or other regulatory procedures.

The minimum data set for the fourth component—hospital care—is known as the Uniform Hospital Discharge Data Set; it was developed by the U.S. Committee on Vital and Health Statistics. The Cooperative System's complex problems with this data set arise primarily from

Competing and often conflicting needs for hospital care data for Medicare, utilization review, professional standards review organizations, health planning, and statistical and other purposes.

Processing problems of meeting timeliness needs.

Increasing problems of protecting an individual's personal privacy.

These and related problems are now under study by a Technical Consultant Panel of the United States National Committee on Vital and Health Statistics. A data set for long-term care, a fifth data component, has been developed and is under review by the United States National Committee on Vital and Health Statistics.

Although ambulatory care statistics, the sixth data component, have not yet received emphasis in the Cooperative System, the methods of the NCHS National Ambulatory Medical Care Survey are being adapted by some States to meet State and local data needs. A minimum data set for ambulatory care, developed by the United States National Committee on Vital and Health Statistics, is now being tested under an NCHS contract.

A similar situation exists with health interview statistics, the seventh component. The National Center for Health Statistics is developing a package survey which can be used by States or localities in making their own health interview surveys. It is not planned, however, that such surveys will reduce the need for, or replace, the National Health Interview Survey.

The plan for enlarging this survey's sample, to provide estimates for smaller geographic areas, has already been noted.

The seven components originally defined for the Cooperative System do not include all the health data needs. Lacking, for example, are services provided by such entities as health departments, health care expenditures and financing, and environmental and social hazards. These topics will be discussed in connection with problems and priorities of the System.

State Cooperative System operations.—Forty-five States, at the end of September 1976, had one or more components of the Cooperative Health Statistics System in an active or developing stage. Of these 45 States, 14 had considerable coordinative activity, usually in the form of a State health statistics center. Such a center is usually found in the health department of the State government; but coordinating

activities are administered in a few States by State human resources departments, planning agencies, the Office of the Governor, or by nongovernmental agencies.

The Cooperative Health Statistics System requires this network of State centers to serve as focal points to insure that health statistical data will be assembled and analyzed. Such centers might have a direct responsibility for primary data collection and activities of one or more of the Cooperative System components, or might serve as the lead agency or coordinator for data collected by other agencies. The State center might also process such data or might contract for processing by another agency. The center would make such data tapes and other output available to users when appropriate.

These centers should have the capacity to analyze health-related data. They should also be able to provide consultation to planning agencies and other data users on the interpretation, limitations, and potentialities of available data and to advise on needs for additional information and ways in which it can be secured.

These centers might be part of a public agency, such as the State health department, or might represent a consortium of data producers and users.

At the present time there is no clear designation of, or mechanism for the designation of, these centers. At the same time there is some urgency for making some designations, both for legal purposes (Health Planning and Resources Development Act, Public Law 93-641) and for furtherance of the development of the Cooperative System.

To assure that such centers receive proper recognition and support, it is essential that they be designated by the State governor or other appropriate public official who can insure that public, private, and voluntary interests have been considered, that legal sufficiency exists, and that the public interest will be served.

Criteria for a State Health Statistics Center should include:

1. Commitment to the System's principles, with evidence of interest and leadership in meeting needs for reliable, timely, and comprehensive data on health status,

resources, utilization of services, and expenditures;

2. Current activities which include the collection, or the coordination of collection, of some of the established data sets in vital records, health facilities, health manpower, and/or hospital discharges, under minimum statistical standards established by the Cooperative System, and conformance to uniform procedures for coding and processing information;
3. Use of statistical methods which are found to be acceptable by independent peer groups;
4. Evidence that the agency or organization does, or is willing to, guarantee to provide equal access to the data it collects to other members of the Cooperative System and other appropriate users, with access limited only by the provision of guarantees by the recipients of nondisclosure of privileged information;
5. Evidence of analytical ability which will result in coordination and assessment of data from the several components, for purposes of planning and decision-making;
6. Establishment of plans and priorities for future expansion of coverage of data components;
7. Indication of coordination of data collection and analysis efforts within the State—such as the establishment and active role of a board, advisory committee, or other organized group which includes major data producers and users.

When an application for acceptance as the State center is received from an organization in any State, the System should review the application with these criteria. If satisfied that such a designation is in the best interests of the State and the Cooperative System, it may enter into a written agreement with the organization to that effect. There may also be a financial contractual arrangement, but this is not to be considered as essential for such designation.

Technical cooperation and assistance.—The participants in the Cooperative System—both public agencies and private organizations—receive technical and financial assistance and support from the National Center for Health Statistics.

Cooperative System participants have the opportunity to share in the development and review of uniform minimum data sets in health-related areas. They also have the opportunity to assemble data for their own jurisdictions or areas of concern with some assurance of completeness, quality, timeliness, and comparability with data similarly assembled for other jurisdictions and subject matter areas.

In addition, they can receive technical assistance as resources permit. The National Center for Health Statistics has instituted this program of continuing communication to provide information sharing, including workshops on program issues, among all participants.

A data application and research focal point, established within the National Center for Health Statistics, plans to develop the capacity to develop, test, and demonstrate the application of special tabulations and analysis of data generated by the Cooperative System. This entity will also carry out special research and development in the problem-oriented analysis of data for local planning purposes. The identification of subject areas and actual problems will be accomplished through a continuing exchange with local and State health planners, managers, demographers, and regulatory agencies as well as the National Center for Health Statistics and other Federal organizations. The solutions would be provided through a mix of State, local, and Center staff and outside contractors.

The methodologies developed as a result of this activity will be given to users in the form of technical assistance, the National Center for Health Statistics training program, or direct exchange with the initiating agency or planner.

Participants in the Cooperative System will be able to take advantage of specialized training opportunities for their staff members, thereby assisting them in improving their data analysis ability. The training program now includes the short courses offered through the National Center for Health Statistics Applied Statistics

Training Institute and work sessions to address technical concerns.

The Cooperative Health Statistics System also provides financial support, usually under contract on a cost-sharing basis, for developmental, operational, and program coordination activities related to the Cooperative System. Until recently, this support has been on a component-by-component basis, and principally for four components—vital statistics, health manpower, health facilities, and hospital care. Each contract has been monitored separately by a project officer with an appropriate technical background.

It has become apparent, however, that this method made no provision for coordination of the individual components toward the interrelationships necessary to a total health information system. Accordingly, in several States, the scopes of work have now been designed to develop and demonstrate the feasibility of coordinating the various component activities within the State.

The concept of coordination is necessary to establish a single viable State system. There are two major benefits in developing a policy of multicomponent single contracts. First, it would provide for coordination of individual components toward the interrelationships necessary to a total health information system. And second, it would give the States flexibility in disbursing funds among components. Inherent in the current system is the lack of any provision which would allow a State to begin the development of components of the Cooperative Health Statistics System without the negotiation of an additional single contract.

Under the provisions of a single multicomponent contract, a modification to the scope of work and additional funds could provide for the initial planning and development of another component. It could also result in more economical use of staff and funds in the States since it would permit much more flexible use of resources.

This new funding approach would encourage the merger of research and development of data systems activities, with a focal point in each State which coordinates its activities with the National Center for Health Statistics. In

summary, it should make possible the development of meaningful State health statistics centers.

Transitional Phase

Today the Cooperative Health Statistics System is in a transitional phase; new systems are being developed as existing systems adapt to expanded sources which can more directly provide health data to multiple users at State and local levels.

There are a number of programs now in operation which collect data similar to those collected under the Cooperative Health Statistics System. In the area of health manpower, several health professional associations conduct periodic inventories—several of them with support from the National Center for Health Statistics. In the area of health facilities, the American Hospital Association makes an Annual Survey of Hospitals, with some support from the National Center for Health Statistics. The National Center for Health Statistics concurrently conducts activities related to the Master Facility Inventory. Hospital care data are also collected as a national sample through the Hospital Discharge Survey conducted by NCHS.

The National Center for Health Statistics will continue to seek the cooperation of private organizations collecting data similar to those being collected in a Cooperative System component—particularly with the goal of minimizing the burden on respondents caused by duplicate inquiries. However, where such organizations do not meet the goal of providing data responsive to the needs of multiple users at national, State, and local levels, the National Center for Health Statistics will develop and implement components of the Cooperative Health Statistics System to meet those needs. A certain amount of duplication is probably necessary, and in some cases important, for reasons of access or timeliness. In most instances, however, it is too burdensome and expensive and should be minimized as rapidly as possible.

To that end, the National Center for Health Statistics and health manpower professional associations are collaborating to provide national inventory data on manpower without duplica-

tion of data collection. These professional associations obtain data through the State licensure process for States not funded through the Cooperative Health Statistics System. These data, together with data from the Cooperative Health Statistics System funded States, provide the basis for national figures on the health profession.

Problems.—In recent years a complex of related and partially conflicting principles and doctrines on confidentiality, freedom of information, and invasion of privacy have received extensive attention. The confidentiality of data is critical to society's wise handling of information. Yet there exists nothing that approaches a satisfactory synthesis of decisions in this area as it relates to a cooperative Federal-State-local system of health statistics.³ The Bureau of the Census, the U.S. Bureau of Labor Statistics, the National Center for Health Statistics, and certain other Federal agencies have traditionally given assurances of confidentiality.

The competing doctrines—the value of such assurances of confidentiality, the principle of freedom of information, the economy of using the same data by more than one agency for more than one purpose, and the conflict between “need to know” and “right to privacy”—constitute the central problem. The economy aspect is one of the key reasons for building a cooperative statistical system among local, State, and Federal agencies in the health field. Yet operating agencies, especially at the State and local levels, need to use specific data for various administrative purposes. These data, often identifying individuals or business establishments, complicate the maintenance of confidential handling by statistical agencies of the same or allied data.

There must be an appropriate balance between a person's right to personal privacy and society's need for information about itself in order to control its activities. This principle is consistent with the basic objective of the Cooperative Health Statistics System. Today Federal law recognizes the concept of protected data and gives adequate protection to data

acquired by the National Center for Health Statistics when the providers have been given assurances of confidentiality.

Yet resolution of the more complex problems that arise with the growth of, and multiple use of, the data generated and processed through the Cooperative System requires the drafting and adoption of a model State law which can serve as both a starting point and a coordinating influence on an emerging body of State law and regulations.

Another problem to be solved is the gaps in data elements. The Cooperative Health Statistics System began developmental work and operation with the identification of seven data components, related primarily to health status, health resources, and utilization of health services, with at least several of the data components contributing to knowledge in more than one of these areas. There are, however, additional areas in which basic work must be undertaken. These include the provision of health services in settings other than those included in the established data sets, costs and financing of health services, and the impact of environmental and social hazards to health. Present data sets do not permit a comprehensive analysis of the relationship between organizations and individuals providing health services and the health of the population to be served—particularly their patterns of utilizing services, their health problems, and their changes in health status. The pattern of inpatient, ambulatory, and community services received by an individual from a single organization or from several providers, including public agencies, cannot be identified, nor can services provided be linked to needs of the population.

Cost and expenditures data now come from a variety of sources, all piecemeal and impossible to put together. Yet, as the cost of health services increases, and seems likely to increase sharply in the near future, the need for comprehensive data in this area is becoming more urgent.

Even less work has been done in the development of data on environmental and social hazards from the perspective of public health. Yet much could be done in this area, even now, by an appropriate analysis of available

³Ibid.

data on health status, hospitalization, and deaths from conditions already known to have a large component of environmental onset or development.

Cost sharing is another problem that needs to be solved since a fundamental principle of the Cooperative Health Statistics System has been that its costs should be shared on an equitable basis by participating agencies and organizations. During the period of program initiation and testing, the National Center for Health Statistics provided funding through contracts for the development, evaluation, and programs established for the collection, processing, and analysis of data. Now, there are States which receive some funding through this contract mechanism. Additionally, the States have for many years received nominal payment, on a record unit basis, for vital record data transmitted to the National Center for Health Statistics.

As the Cooperative System grows, there is an urgent need to cope with the problems of cost sharing. For this reason, the Cooperative Health Statistics Advisory Committee has established a Cost-Sharing Task Force which studies these problems. This Task Force has developed preliminary guidelines for cost sharing for the vital records and is now working on similar guidelines for other components. The Task Force notes, however, that other types of problems must be faced. These include

Cost-sharing guidelines for States wanting to negotiate a single contract to implement several components and combine the staff and other resources.

Payment when State systems are being used to meet other Federal data needs, such as health systems agencies' requirements, which result in an enlargement of the record or expansion of work beyond the Cooperative Health Statistics System requirements.

Cost-sharing guidelines when the partner is an organization or agency other than the State government.

To respond to the mandate of Congressional legislation and to meet urgent needs for data to plan and evaluate various Federal health programs, the Federal agencies must work more

closely with States to develop the Cooperative System. Since the technical development of this System is ahead of the resources needed for implementation, the program will require a sharp increase in funding over the next few years.

Priorities.—Although it may be impossible to rank the present and future needs for system development and operation, two immediate priorities are

Development of an adequate financing structure which includes mechanisms and guarantees of appropriate funding by transfer of funds among the programs of the Department of Health, Education, and Welfare to assure that Departmental agencies benefitting from the Cooperative System provide their fair share of the operating costs.

Development of State health statistics centers with general responsibility for the development, integration, and analysis of health-related data from the Cooperative System's data components and from other appropriate sources. Because the output of these State centers will be important in public decisionmaking, there are advantages to having the control at the State level in a public agency. It may be appropriate, in some States, for such centers to make subcontracts with other organizations or data brokers. However, this should be done with the objective of strengthening the concept of a State health statistics center.

It is apparent that a successful system cannot emerge from the independent growth of area or subject matter components, no matter how well-designed and executed they may be. Of overriding importance is the establishment of State centers that will give a purpose, a focus, a direction, and an integration of the Cooperative System.

A principal objective of the Cooperative System is helping States to bring together a body of information with which they can meet their planning, regulatory, and other needs. If this were not the case, sample studies would suffice for most national statistical purposes.

It is of primary importance, therefore, to help States to identify their needs and to make the best use of available data to meet present urgent needs. Even if all of the seven identified components were neatly in place, the needs of the States would not be met. The States, therefore, must view these components as "helps" in meeting their needs and not entirely as "ends" in themselves. Priorities in developing component areas are also of importance.

Vital statistics must be given precedence since they are not only basic to planning and problem identification in the States, but State activity in this area is essential for national use.

Data on resources, both facilities and manpower, should be placed next in priority. Data on the location and types of services

provided by hospitals and other health care facilities is essential for planning and for regulation. Similar data on other care facilities are almost as important.

Utilization of hospitals and other facilities is also an area of high priority. Several States are conducting developmental and demonstration activities in three utilization components—hospital care, ambulatory care, and long-term care. Other States are fostering coordination among data collectors and users in their State and are encouraging the development of a consortium of such interests. However, organization roles at the Federal level need to be resolved and lines of technical cooperation must be further defined before there can be a rapid implementation in this area of urgent data needs.



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