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**Part I**  
**Coordination Issues**

## SUMMARY

The Federal role in health care has grown rapidly since the passage of Medicare and Medicaid legislation in 1965. During the past 15 years, Congress has enacted scores of programs relating to health, including those that provide medical services, train health professionals, assure access and quality of medical care, control medical care costs, and regulate the adverse effects of the environment on health. Furthermore, Congress has also broadened traditional public health programs, which were designed primarily to control communicable and preventable diseases and to support biomedical research.

The health data collection systems of the Federal Government have grown dramatically in large part because of the expanding Federal role in health care. The increase in both the numbers and types of Federal health programs has produced a concomitant growth in the demands for information. Decisionmakers demand not only more health data, but also increasingly sophisticated health data. Each new program creates unique reporting needs for effective and efficient management, planning, evaluation, and congressional and public accountability. Hence, virtually every new Federal program has spawned a data system that separately acquires data to fulfill its own program needs.

The purpose for which health data are needed largely dictates the design of a health data collection system. The Federal Government acquires health data for program management and evaluation, regulation, research, and policymaking. Attributes of a statistical system that may vary as a function of purpose include: the timeliness and availability of data, the periodicity of collection, the number and types of respondents, the geopolitical detail, and the requirements for data quality (validity and reliability). For example, necessary quality requirements of data used for management decisions are usually less rigorous than those used in research. The Department of Health, Education, and Welfare (HEW) makes a distinction between general purpose and program-specific statistical systems based on function (26). General purpose systems are defined to include baseline data that are available to multiple users; they are produced by data systems that only collect statistical information. Program-specific statistical systems, in contrast, produce data as a result of activities primarily directed toward facilitating overall project management. This distinction does not appear to be particularly useful, however; excluding the statistical projects of the National Center for Health Statistics (NCHS), all data collection systems in HEW have evolved from specific program needs.

The rapid proliferation of such program-specific health data projects has exacerbated the decentralization of the Federal health statistical system. A decentralized system may increase the responsiveness of data projects to the needs of individual agencies, but it inevitably creates difficulties in planning and coordination. Too much data are collected in some areas, duplicating expensive resources, and too little data are collected in other areas. As new needs for information arise, the system leaves few alternatives to initiating more data collection activities. Other problems that currently characterize health data collection systems include fragmentation, respondent burden, inefficient use, and an inability to collect data that cut across agency jurisdictions.

Incentives for coordinating diverse data collection activities are minimal because the growth in data-gathering activities has occurred to meet the program needs of administrative agencies and regulatory efforts. The limited ability of existing statistical policy offices to orchestrate and plan data activities of administrative agencies is another obstacle to coordination. The information collected for, and used by, individual agencies also may be difficult to organize because Congress does not consider and coordinate data requirements as it passes legislation. In fact, many Federal agencies cite legislative requirements as the reason for the proliferation of health data systems. Part II of this report presents a directory of statutes that authorize the collection of health data by the Public Health Service (PHS) and the Health Care Financing Administration (HCFA) in HEW. It is designed to determine the extent to which legislation creates or furthers fragmentation and duplication in Federal health data systems.

## SCOPE OF THE REPORT

This report discusses the, need and opportunities for coordinating health statistical activities of the Federal Government. It focuses, in particular, on the variety of HEW data collection activities and coordination attempts.

The purpose of this report dictates the use of a broad definition of "health data." The terms "data," "information," and "statistics" are used interchangeably. Health data are defined as information describing the health status of people, their use of medical care services and resources, and the costs and sources of funding for these services. Data relating to health effects of the workplace and the environment, diseases, health problems, and health conditions are included in this definition. Finally, data on public knowledge and attitudes about health, perceived health needs, and behavior related to health, health care, and health practices are also included.

The report does not address the quality and the value of individual data collection systems. The discussion is also limited to Federal endeavors; health data systems operated by the private sector and those administered by other levels of government are not examined. Consideration of how the Federal statistical system should relate to other data collection activities is outside the scope of this report.

A number of other important issues that relate to health data policy are not specifically addressed in this study. For example, there are problems of consistency in policies regarding confidentiality of health data. Provision of data on a small area basis is another area of national concern that is not discussed. This report considers various possibilities for structuring efforts in HEW to achieve comprehensive and consistent policies relative to health data collection systems.

## FINDINGS AND CONCLUSIONS

The growth in Federal data activities is demonstrated by the increase in the number of health data projects operated by PHS, the major collector of health statistics. In FY 1977, PHS administered 153 data projects, more than a one-quarter increase over the number operated the previous year. HCFA, the other principal component within HEW concerned with health issues, operated at least an additional 13 large statistical projects that year. Seven agencies and departments outside of HEW also conduct major health statistical activities in pursuit of their missions.

Accurate figures on the costs of administering this great variety of health data systems are difficult to obtain. The Office of Management and Budget (OMB) estimates that total expenditures for Federal health statistical activities in FY 1977 were \$100 million. PHS agencies, which all operate health data programs, spent more than \$80 million of this amount. OMB'S estimates are conservative, however, because available information severely underreports the costs and numbers of data collection projects.

The Federal Government lacks a coherent policy to organize and manage the increasing numbers of assorted data collection projects. Activities relating to the acquisition, analysis, and use of statistical data that describe the health of people and the utilization of medical care services and resources are unstructured and decentralized. There is no systematic and comprehensive appraisal of the adequacy or use of health data presently collected.

The U.S. statistical system, although sophisticated and generally responsive to the needs of those who operate Federal health programs, is characterized by a number of serious problems. The range of deficiencies in the health statistical systems highlighted in this report are outlined below. As indicated above, the majority of these problems stem from the fact that the growth in Federal health data efforts has occurred primarily outside agencies with major statistical responsibilities.

- s The categorical design of Federal endeavors results in duplicative and fragmented data collection efforts.
- There is no central body, accountable to Congress and the public, that serves as a reference for providing information regarding what and how health data can be located.
- Data projects designed for the administration, evaluation, or regulation of specific health programs are not responsive to the needs of the spectrum of potential users.
- The potential utility of available data is not being realized because of limited access to data.
- q Decisions regarding data collection, use, timeliness, and publication are made on an ad hoc basis by the acquiring agency.
- The lack of common nomenclature, definitions, classifications, codes, and units of measurement creates serious obstacles to fully linking data systems, and results in an increasing incidence of data overlap, gaps, and underutility.
- The inability to integrate and link diverse data files for analyses that require more than one data source makes it difficult to assess program achievements, to compare programs, to determine the relevance or meaning of data, and to form statistical profiles about a particular issue or problem.
- . Staff of administrative agencies often do not have the necessary statistical and analytical skills to utilize the latest statistical technologies. The effective and efficient supervision of data projects may also be hindered by the Federal Government personnel system, which restricts interagency movement of statisticians.
- The Federal health statistical system lacks an overarching set of principles and objectives that can be employed to rationally plan data activities, to allocate resources for data collection, and to comprehensively and systematically evaluate current data projects.

- The absence of an administrative unit that supervises statistical activities and gathers and provides accurate information regarding the type of data collected and the method and cost of data collection is one of the system's major deficiencies.

A number of offices currently have authority to establish policy concerning health data systems. OMB and the Department of Commerce have responsibilities relating to statistical oversight for the entire Federal Government. The coordination activities of these offices are authorized under the Federal Reports Act of 1942 and the Budget and Accounting Procedures Act of 1950. At least five offices and three committees within HEW also have been delegated some coordination duties. However, a number of these offices are charged with similar health data policy, oversight, and coordination responsibilities, and consequently, their activities tend to be duplicative.

There is a need to assign formal responsibility for the functions related to the coordination and planning of Federal health statistics to a central coordinating body within HEW. Such a unit should have sufficient authority to impose decisions on agencies and offices in the department, the necessary statistical and analytical capabilities to conduct activities requiring technical expertise, and adequate resources to build a viable core effort. The coordinating unit should perform three essential functions: developing an analytical framework for planning the statistical system, improving the efficiency of data collection activities, and ensuring data accessibility for potential users.

A number of offices within HEW could assume responsibility for comprehensively supervising Federal health statistics. Different offices could be accountable for activities requiring authority over substantive program agencies and for activities requiring technical capabilities. Additional staff and funding would be required regardless of which office or offices are selected. The fundamental requirement in assigning responsibility is an unambiguous mandate to manage health statistics.

## ORGANIZATION OF THE REPORT

The report is organized into two major parts. Part I consists of three remaining chapters, Part 11 is a directory of statutory authorities that may be used to justify health data collection by agencies within PHS and HCFA.

Chapter 2 of Part I presents and briefly describes a number of existing data collection systems administered by HEW and other major Federal departments and agencies, such as the Department of Defense (DOD) and the Veterans Administration (VA). Within HEW, the health data activities of PHS and HCFA are reviewed. The overview of data collection systems is designed to be illustrative, not exhaustive.

Chapter 3 discusses activities presently conducted by Federal agencies that have responsibilities for health data policy, oversight, and coordination. The responsible Federal agencies are described hierarchically, beginning with OMB and the Department of Commerce—the two executive branch components charged with Government-wide statistical oversight responsibilities. The remaining sections of the chapter describe offices and committees within HEW.

Chapter 4 of Part I describes a structure designed to improve the coordination of Federal health statistics. Requisite functions and activities are delineated. The need to formally assign responsibilities is discussed and alternative locations within HEW for such delegated authority are identified.

Part II of this report focuses on legislation that may be used to generate health data collection projects. The directory is designed to determine the extent to which legislation creates or amplifies fragmentation and duplication in HEW health data collection. Data collection authorities are listed according to PHS and HCFA agencies that have been delegated responsibilities for their implementation. This directory contains all the relevant statutory authorities enacted before January 15, 1979.