Chapter 2.

OVERVIEW OF EXISTING HEALTH DATA COLLECTION ACTIVITIES

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INTRODUCTION

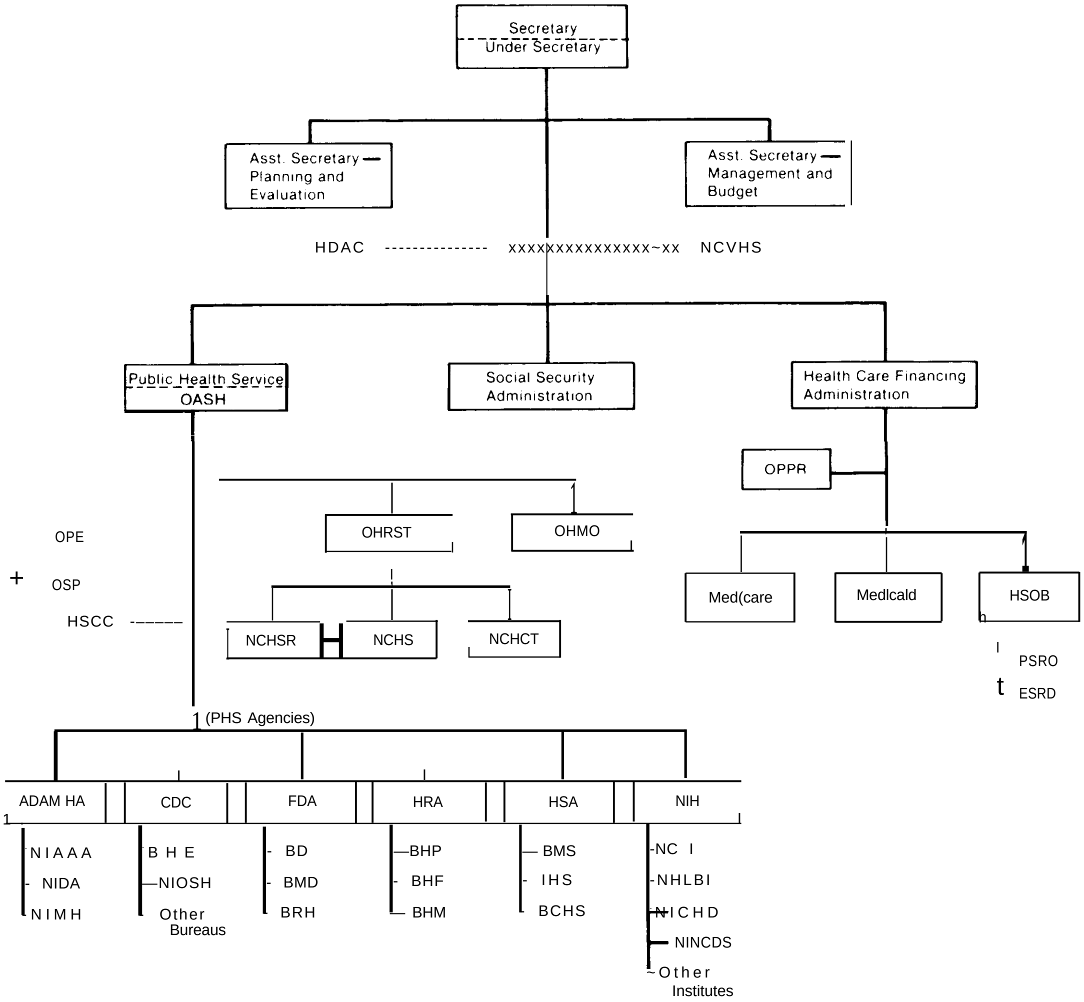
The Department of Health, Education, and Welfare (HEW) is the major collector of health statistics. Authority to administer data projects has, for the most part, been delegated to the Public Health Service (PHS) and the Health Care Financing Administration (HCFA), the two principal operating components of HEW concerned with health. In FY 1977, PHS operated 153 data projects, a 25- to 35-percent increase over the number of projects operated in the previous fiscal year (41, 42). HCFA administered at least an additional 13 large statistical projects. Other Federal agencies and departments, such as the Veterans Administration (VA), the Department of Defense (DOD), and the Consumer Product Safety Commission (CPSC), also operate a number of health statistical systems, independently of HEW, to meet their needs for information.

This chapter begins with a discussion of health data systems and health data collection. It provides background information on Federal expenditures for health statistics and describes a number of health data collection activities. The inventory of Federal data systems presented here is meant to be illustrative and descriptive, not inclusive and analytical. The focus of chapter 2 is on the statistical projects and systems administered by HEW; they are described first. Within HEW, the health data collection activities of PHS and HCFA are highlighted. Figure 1 illustrates the organizational position of HEW agencies discussed in this chapter. A discussion of data activities managed by other Federal agencies, including those mentioned above, follows. These agencies are illustrated in figure 2.

A health data system is defined as an organized, systematic acquisition and classification of health information. This definition encompasses a broad spectrum of data systems that are difficult to tally and compare because of the diversity in their purpose, scope, and cost. Data for these systems may be collected on a continuing or a periodic reporting basis; or, they may be gathered in a survey, conducted at a point in time or over a specified time interval. Data can be collected on a sample, or on a universe of respondents. They may be acquired either from a primary source, such as a questionnaire, an interview, or a physical examination, or from a secondary source, such as a billing claim or a health professional license. When data are obtained for, or as a result of, an activity not specifically related to data collection (i. e., a secondary source), these data are frequently referred to as byproduct statistics.

A major expansion has occurred in the area of byproduct statistics because more data are being obtained either for the administration of Federal programs or for regulatory purposes. The statistical output of the Medicare Bureau, for example, is derived from four basic computer files that are centrally maintained for paying the medical bills of eligible beneficiaries. Determining the number of health data systems in the Medicare

Figure [illegible].—Department of Health, Education, and Welfare Organizational Components Involved in Health Data Activities*##

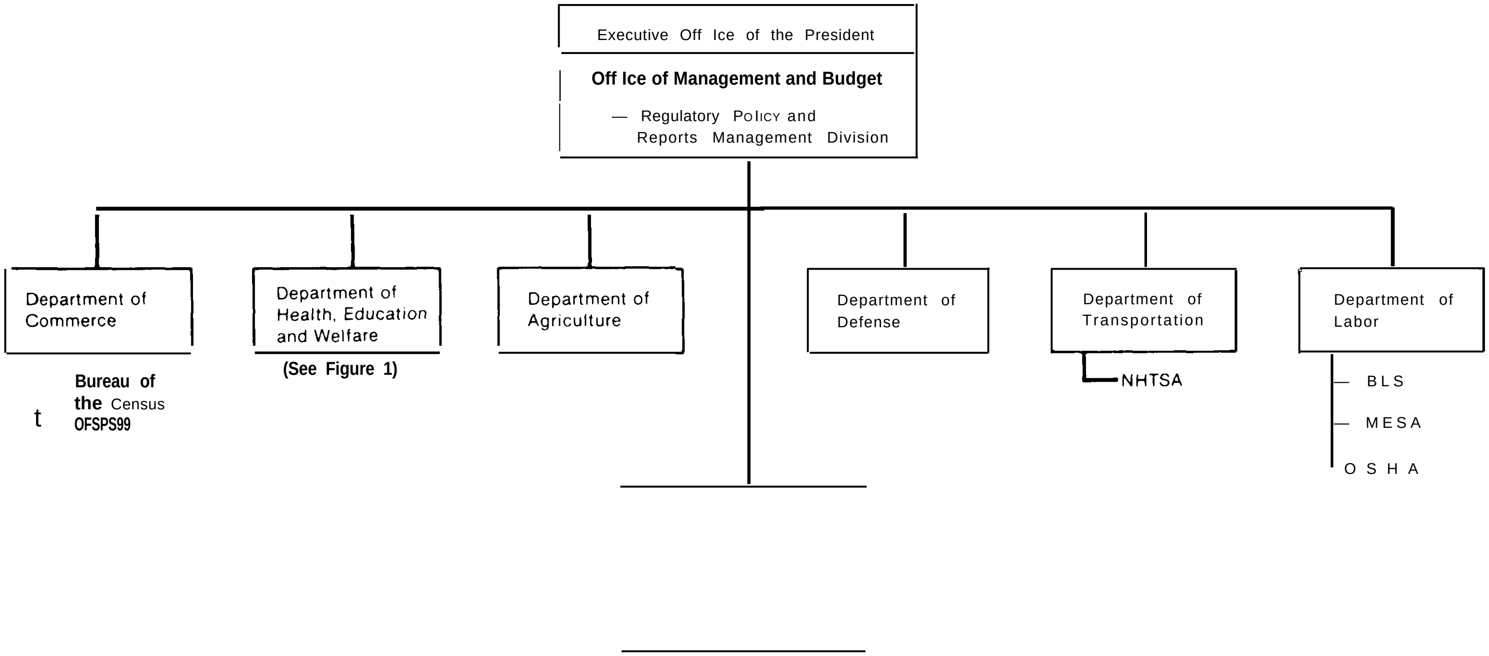


“ This diagram depicts only those parts of HEW that have major responsibilities for health data policy, collection, or coordination.

Full names of components are given in the Glossary of Acronyms, p. xi.

Code” ------ Internal Advisory Committee
XXXX External Advisory Committee

Figure 2.—Federal Executive Branch Components Involved in Health Data Activities*



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*This diagram depicts only those parts of the executive branch that have major responsibilities for health data policy, collection, or coordination

Full names of components are given in the Glossary of Acronyms, p. xi.

program is problematic. The program's four basic files or its computer programs, which are written to retrieve, integrate, and display data, could be counted individually as discrete data systems.

As the numbers and types of health data systems increase, so do their costs. HEW is the primary source of information about health data systems because it administers the majority of Federal health programs. Under the auspices of a departmentwide committee, descriptive, cost, and other information on individual data projects are collected through questionnaires distributed to agencies and are published in the HEW annual inventory of statistics (40, 41, 42). In an attempt to be inclusive, data projects, rather than data systems, are used as the criteria for inclusion in the inventories. Single-time surveys and evaluation and research studies that contain a large data collection component are listed in HEW's statistics plans. Biomedical research and studies funded by Federal grants are explicitly excluded from these inventories.

The Office of Management and Budget (OMB) also supplies information on the costs of Federal health statistical projects. OMB derives its figures from the budget review process, which requires every agency to submit statistical budget requests for data collection projects. Table 1 illustrates FY 1976 and FY 1977 PHS expenditures for statistical projects as reported in the HEW statistics plans mentioned above. OMB'S data on PHS expenditures for the same fiscal years are contrasted in table 2. OMB'S estimate is approximately 20 percent greater than HEW's; estimates for individual PHS agencies vary even more.

Different administrative mechanisms used by OMB and HEW to collect agency cost figures partially explain the variation in their estimates. Budgeting personnel prepare statistical budget requests for OMB, and agencies that incur obligations of less than $300,000 for statistical programs are exempted from filing budget requests. Program planning staff complete the questionnaires for HEW's statistical plans. HEW reports direct costs associated with individual data projects. OMB'S cost estimates include the substantial administrative expenses of maintaining data systems. OMB'S estimate for the National Center for Health Statistics (NCHS), for example, includes that agency's entire budget; HEW reports costs only for NCHS surveys.

The accuracy of OMB and HEW estimates is questionable because of the difficulty of obtaining complete cost figures for Federal data activities. Available information severely underestimates Federal expenditures on health statistical projects. Information pertaining to expenditures for a number of statistical activities are often omitted by agencies in their reports to both OMB and HEW; and expenditures for statistical projects supported by Federal grants and contracts are vastly underreported. Administrative costs for statistical activities conducted by HEW-supported categorical programs, such as medical treatment centers in underserved population groups and health planning agencies, are usually not reported. For example, HCFA reported to OMB total obligations of $4.8 million in FY 1977 for health statistics (25). However, data processing expenditures by local Professional Standards Review Organizations (PSROS), although covered under Federal contract, are not included in HCFA'S statistical budget request to OMB. Rather, HCFA reports expenditures only for processing and analyzing data sets forwarded to the central PSRO office. In FY 1977, local PSROS spent $2.2 million for data processing; HCFA central office costs were only $380,000 (7). If all these costs were included in

Table 1 .—Public Health Service Expenditures for Health Statistics Projects, as Reported by the HEW Health Statistics Plans* (in millions of dollars)

Agency	I% 1976a	w 1977b
Alcohol, Drug Abuse, and Mental Health Administration.	5.7	6.5
Center for Disease Control.	2.7	2.8
Food and Drug Administration	1.3	1.9
Health Resources Administration.	21.5	1.5
Health Services Administration.	3.7	3.2
National Institutes of Health	19.9	33.2
Office of the Assistant Secretary for Health	2.6	20.0
Total	57.4	69.1

‘ **PHS** warns that their cost estimates may not be comparable from year to year and that they represent “order of magnitude” figures

[a] **SOURCE** Public Health Service, U S Department of Health, Education, and Welfare health Statistics *Plan, fiscaLFmca/ Years* 1978.1982 Washington, D.C : U S. Government Printing Off Ice, 1977

b SOURCE publlc Health Service, u s, Department of Health, Education, and Welfare Health STATISTICSfatlSfKs *~ePorf, Fiscal Year 1978 washlngton,G9GTONon,* D. C.: U.S. Government Prlntlng Office, 1978,

Table 2.—Public Health Service Expenditures for Health Statistics Projects, as Reported by the Office of Management and Budget (in millions of dollars)

Agency	FY 1976a	FY 1977b
Alcohol, Drug Abuse, and Mental Health Administration	6.8	8.5
Center for Disease Control.	2.5	3.0
Food and Drug Administration	1.6	1.9
Health Resources Administration.	32.0	4.5
Health Services Administration.	2.4	4.1
National Institutes of Health	23.4	29.3
Office of the Assistant Secretary for Health	—	32.4
Total	68.7	83.7

[a] SOURCE: Office of Management and Budget *Speclal Analyses, Budget of the United* States *Government,Fiscal Year 1978* Washington, D C U.S. Government Printing Office, 1977

b SOURCE. Of flee of Federal Statlstlcal Policy and Standards, U.S Department of Commerce “Federal Statistics 1977.” *Stat/sf/ca/ Reporter* 78-5 121-140, February 1978

estimates of Federal expenditures for statistical projects, OMB's total estimate of $100 million for health statistics could triple. *

Neither OMB nor HEW provides adequate followup on its requests to agencies for information on statistical projects, and no uniform methods for calculating the costs of data collection are imposed. Agencies have difficulty in isolating cost figures solely related to data gathering activities that are a part or a byproduct of a program’s administrative expenses. Without appropriate guidelines, definitions, standards, and followup, inconsistencies among costs reported by HEW agencies for their statistical programs are inevitable, and inaccurate and noncomparable estimates will continue.

DATA COLLECTION ACTIVITIES OF THE DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

The Department of Health, Education, and Welfare (HEW) administers the majority of Federal health programs and health data systems. The following material outlines data collection projects and systems in the Department’s two principal health-related operating components, PHS and HCFA, and in the Social Security Administration (SSA).

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*OMB includes under health statistical programs, in addition to the Public Health Service and the Health Care Financing Administration, certain programs of the HEW Assistant Secretary for Planning and Evaluation, the Consumer Product Safety Commission, the Drug Enforcement Administration, and the Veterans Administration (12, 25).

Within PHS, data activities conducted by the Office of Health Research, Statistics, and Technology (OHRST), the Office of Health Maintenance Organizations (OHMO), and the six agencies are emphasized. Data collection activities supervised by HCFA'S Medicare and Medicaid Programs, Health Standards and Quality Bureau (HSQB), and Office of Policy, Planning, and Research (OPPR) are then discussed. Finally, SSA'S health-related statistical activities are outlined.

Public Health Service: Office of Assistant Secretary for Health

The Office of Health Research, Statistics, and Technology (OHRST) was created as part of an executive reorganization in January 1979. It has responsibility for NCHS, the National Center for Health Services Research (NCHSR), and the National Center for Health Care Technology (NCHCT). Formerly the Office of Health Policy, Research, and Statistics (OHPRS), OHRST was established to strengthen the relationship between health technology assessment, health statistics, and health services research.

The National Center for Health Statistics (NCHS) is the only Federal agency established specifically to collect and disseminate data on the health of the American people. Congress first authorized a continuing survey and special studies of sickness and disability in the National Health Survey Act of 1956, Public Law 84-652. In 1960, the National Health Survey merged with the National Office of Vital Statistics, which was established in 1946, to form NCHS. Since that time, NCHS has played a major role in the development of national health statistics policy and programs. Organizationally, the Center has moved several times within PHS; it is now located in OHRST.

The Health Services Research, Health Statistics, and Medical Libraries Act of 1974, Public Law 93-353, established NCHS statutorily and expanded its responsibilities. The law both listed the categories of general-purpose statistics to be collected by NCHS and mandated that a detailed report analyzing the country's health care costs and financing, health resources, health resource utilization, and health status be submitted annually to the President and Congress.

To fulfill its mission, NCHS conducts a number of data activities that provide vital statistics and health facility, health manpower, and health status and health care utilization statistics. NCHS also has the primary administrative responsibility for the Cooperative Health Statistics System (CHSS), * a joint Federal, State, and local program for the collection of health data.

The NCHS Division of Vital Statistics collects natality, mortality, marriage, and divorce statistics. These statistics are derived either from microfilm copies of State certificates of marriage and divorce and State records of births and deaths, or from the computer tapes supplied through the vital statistics component of the CHSS program. NCHS then publishes statistical summaries based on this State-supplied information. In addition, NCHS periodically conducts "followback" surveys that are based on samples of birth or death records. They are designed both to provide national estimates for a range of items that are not usually included in vital records, such as demographic characteristics, and to evaluate the quality of data contained in the vital records.

The NCHS Master Facility Inventory, initiated in 1962 and updated biennially, furnishes information on all inpatient health facilities that provide medical, nursing, personal, or custodial care, Data are collected on facility ownership, finances, patient population, provision of services, number of beds, and pattern of staffing. Another facil-

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*See chapter 3 for a detailed discussion of the CHSS program.

ity inventory, also updated biennially, supplies information regarding family planning clinics. A third example of a facility data system is the National Nursing Home Survey. Conducted every 2 years, it gathers data from a sample of nursing homes, their residents, and their staff.

NCHS manpower statistics consist of periodic inventories of various health professionals, including physicians, registered nurses, pharmacists, and optometrists. The manpower inventories are conducted only in States that have not implemented the CHSS program. In 1975 and 1976, for example, NCHS conducted a survey of hospital staff. This survey covered 110 health occupations and was used both to identify manpower shortages or oversupply and to assess trends in the recruitment and the employment of allied health personnel.

NCHS also operates five major general-purpose surveys that provide statistics on the health status of the U.S. population and on their use of health care services. The Health Interview Survey (HIS), performed annually since 1957, provides data on the incidence of illness and accidental injuries, the prevalence of diseases and impairments, the extent of disability, the utilization of hospitals and other health care services, and other health-related topics. These data are obtained through interviews conducted in a probability sample of households.

The Health and Nutrition Examination Survey (HANES), * which was initiated in 1971, obtains standardized data from direct physical examinations of a sample of the U.S. population. Data are collected periodically to estimate the prevalence of chronic diseases, to establish physiological standards for various tests, to determine the nutritional status of the population, and to assess exposure levels to certain environmental substances. Data are also collected, through interviews, on self-perceived health needs and health practices. The National Survey of Family Growth acquires data on childbearing and family growth patterns. These data are needed to interpret current trends in the birth rate, to aid in the planning, management, and evaluation of family planning programs, and to provide guidance for efforts in the areas of infant and maternal health. Data are collected through personal interviews with women of childbearing age. NCHS began this survey in 1973.

The Hospital Discharge Survey (HDS), begun in 1965, collects data from the medical records of a sample of patients discharged from a number of the Nation’s short-stay hospitals. Data abstracted from patients’ medical records include demographic characteristics, diagnoses, surgical procedures, and administrative information about the hospital stay. Annual profiles on national and regional hospital use, organized according to diagnoses, procedure, patient characteristics, and other variables, are then published by NCHS. The National Ambulatory Medical Care Survey (NAMCS), first conducted in 1973, gathers data on a number of patient visits from a probability sample of office-based physicians. Participating physicians complete a brief encounter form that requests information regarding patient characteristics, reason for visit, diagnoses, treatment and services, and disposition.

The National Center for Health Services Research (NCHSR) shares responsibility with NCHS, the Assistant Secretary for Planning and Evaluation (ASPE), and HCFA for the National Medical Care Expenditure Survey. This survey represents a cooperative effort between PHS and HCFA to supply data to users who require information on health

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*The Health Examination Survey (HES) Was the precursor to HANES. HES collected data on the health status of adults, between 1960 and 1962: of children, between 1963 and 1965: and of teenagers, between 1967 and 1968.

care costs. Begun in 1976, this large, one-time survey is collecting information from households, physicians, hospitals, and health insurance companies. The survey is acquiring information on expenditures for health care by different population subgroups in relation to utilization, health status, and health conditions. The survey is expected to be completed this year.

The Office of Health Maintenance Organizations (OHMO) requires quarterly and annual reports from qualified health maintenance organizations. Data are collected on enrollment, financing, staffing patterns, and use of services. The reporting system is used for program management, planning, and evaluation.

Public Health Service Agencies

The Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) has the major responsibility within the Federal Government for the prevention and treatment of alcohol abuse and alcoholism, drug abuse, and mental and emotional illness. Its three Institutes, the National Institute on Alcoholism and Alcohol Abuse (NIAAA), the National Institute on Drug Abuse (NIDA), and the National Institute of Mental Health (NIMH), award grants and contracts for research, prevention, training projects, and treatment service delivery in community-based programs.

NIAAA has specific legislative authority to collect information on the cause, treatment, and consequences of alcohol abuse. Its primary data system, the Alcoholism Program Monitoring System, collects data that describe the clients, the services, and the costs of alcoholism treatment programs funded by NIAAA. Data are used to plan, manage, and evaluate programs.

NIDA, which is required by statute to collect uniform statistics related to drug abuse and the availability of treatment resources, operates three major health data collection systems: the Client Oriented Data Acquisition Process (CODAP), the National Drug Abuse Treatment Utilization Survey (NDATUS), and the Drug Abuse Warning Network (DAWN). The CODAP system, also used by the VA and the Bureau of Prisons, gathers client-related data at the time of admission to, and discharge from, federally supported drug abuse treatment and rehabilitation programs. These programs are required to report to NIDA. Data on nationwide resources devoted to drug abuse treatment, their use, and their distribution are gathered through NDATUS. All drug abuse treatment facilities are surveyed annually; however, participation in the NDATUS survey is voluntary. Finally, data on drug-related deaths, medical emergencies, and psychological crises are collected from participating emergency rooms and medical coroners in DAWN, which is jointly sponsored by NIDA and the Drug Enforcement Administration (DEA).

NIMH, through its Division of Biometry and Epidemiology, conducts annual inventories of public and private mental hospitals and community mental health centers. Hospital psychiatric divisions, halfway houses, outpatient mental health clinics, and other mental health facilities are inventoried biennially to collect data depicting caseload, services, and expenditures. Sample surveys are also conducted periodically to gather detailed data about patient characteristics and the use of services. Participation by institutions in NIMH surveys is voluntary.

Presently, NIMH is developing a statistics improvement program that would enhance State and local capabilities for statistical collection and analysis. This Federal-State-local system would be operated independently from the NCHS Cooperative Health Statistics System. Consequently, NIMH and NCHS have established a joint coordinating committee. At present, NIMH's inventory data on mental health facilities are integrated with the NCHS Master Facility Inventory to avoid duplication.

The Center for Disease Control (CDC) is responsible for monitoring and reducing the incidence of preventable diseases. Its two major data reporting systems, the National Disease Surveillance Program and the Morbidity and Mortality Weekly Report, are used to examine disease patterns and trends, to identify regional problems, and to evaluate the effectiveness of control measures. Through a variety of reporting systems, CDC receives summary data from State, county, and city health authorities on 45 specific conditions. These reporting systems are authorized primarily by State laws enacted to control communicable diseases.

CDC maintains special data programs to monitor congenital malformations, abortion-related complications, birth defects, diabetes, tuberculosis, and venereal diseases. The manufacture rates of biologics is also monitored by CDC. Data regarding children's immunity levels against vaccine-preventable diseases are obtained from the U.S. Immunization Survey, which is conducted by the Bureau of the Census under contract to CDC. CDC analyzes the Bureau of the Census data and prepares the reports.

For program evaluation purposes, CDC receives summary data from Federal grant recipients who administer State and local health programs for disease prevention and control. These programs are designed, for example, to prevent venereal disease and lead poisoning, to control rats, and to immunize individuals against preventable diseases. CDC'S Bureau of Health Education (BHE) and the Office of the Assistant Secretary for Health (OASH) are responsible for informing the public about health practices and disease prevention. BHE therefore conducts surveys to determine public attitudes and knowledge on topics such as smoking and immunizations.

Finally, CDC provides support for the regulatory functions of several other Federal agencies. For example, CDC evaluates the qualifications and quality control practices of clinical laboratories for the Medicare program. The National Institute of Occupational Safety and Health (NIOSH), within CDC, assists the Department of Labor's Occupational Safety and Health Administration (OSHA) in identifying occupational health hazards and in establishing workplace health standards. The National Occupational Hazard Survey, conducted by NIOSH between 1972 and 1974, provides estimates of the proportion of employees exposed to potential health hazards in various industries. In addition, NIOSH periodically conducts special industrywide studies to identify the health effects of particular industrial processes and to determine the health experience of selected employee populations. NIOSH also operates the National Surveillance Network which receives data from State safety and health inspection programs that describe employee exposure to health hazards. Finally, an X-ray examination program for coal miners to determine the prevalence of black lung disease (pneumoconiosis) and to provide epidemiological data for research is operated by NIOSH.

The Food and Drug Administration (FDA) is responsible for evaluating the safety of food, drug, cosmetic, and medical device products before their introduction into the marketplace. It evaluates the efficacy as well as the safety of new drug and medical device products. FDA also monitors manufacturer compliance with its regulations.

FDA conducts a number of special surveys and studies on topics ranging from consumer attitudes on, and knowledge of, nutrition to the use of selected drug products in clinical practice and the health effects of exposure to specific types of radiation.

FDA supports four major ongoing health data collection projects. The FDA Bureau of Drugs (BD), in collaboration with the National Institute of General Medical Sciences in the National Institutes of Health (NIH), funds the Boston Collaborative Drug Surveillance Program (BCDSP). BCDSP monitors selected inpatient populations to determine rates of adverse reactions to certain drugs and provides data on overall drug use in the sampled population. BD also maintains a central system for reporting the incidence of adverse drug reactions. However, statistical analyses of data are not possible because reporting is voluntary and there is no sampling plan.

The Bureau of Radiological Health (BRH), operates the Nationwide Evaluation of X-ray Trends (NEXT) system, the second major health data collection project operated by FDA. NEXT is designed to detect and evaluate the extent of the population's exposure to X-rays used in medical and dental examinations. Data are collected from a sample of hospitals, private offices, and clinics in States that participate in the survey.

The Medically Oriented Data System, the third data project, is operated by the Bureau of Medical Devices (BMD). It is designed to analyze data collected from a small sample of hospitals on drug abuse, medical device injuries, and other hospital-based health hazards. BMD also operates the Medical Devices and Laboratory Product Problem Reporting Program; this system uses information collected by other agencies that participate in the Devices Experience Network (DEN), a central network for all reports concerning problems with medical devices.

The Health Resources Administration (HRA) is concerned with the identification, development, and effective use of national health resources. A new administrative unit, the Bureau of Health Facilities, Financing, Compliance and Conversion (BHF), was established in HRA by an executive reorganization in 1978. BHF operates a data system that contains information on all health care facilities seeking grant or loan support under the Hill-Burton program. The Hill-Burton reporting system has been modified a number of times reflecting some conflict over the specific purposes it should serve.

The Bureau of Health Planning (BHP) oversees a nationwide network of local and State health planning agencies. These planning agencies are expected to compile and analyze data on the health status of residents in their area and on the effect of the area's health care resources. Federal guidelines establish minimum requirements specifying categories of data to be collected, but these data are not required to be forwarded to BHP. However, local and State agencies must submit annual health plans to BHP.

To the extent possible, local agencies are expected to rely on data assembled from other sources. Although substantial progress has been made, health planning agencies have had difficulty in obtaining data of appropriate geopolitical detail. They do not have the funding resources necessary to undertake major data collection activities that would fulfill their needs for small area data. Therefore, plans are underway to obtain selected program data for the areawide agencies from the Medicare program and from NIMH. In the future, CHSS is expected to provide much of the data needed by the planning agencies.

The Bureau of Health Manpower (BHM) is mandated by its enabling legislation to meet extensive data requirements relating to health manpower supply, demand, specialty, productivity, and geographic distribution. Data that may be used to delimit the critical level of health manpower needed to adequately serve areas are also required from BHM. Special studies and surveys of various categories of health manpower are conducted by BHM to fulfill some of its requirements. Examples of such surveys include a national sample of registered nurses and studies on the delivery of dental care by various types of dental personnel. BHM and NCHS have a formal agreement under which inventory data on various categories of health manpower are supplied by CHSS; this agreement is restricted, obviously, to the States in which the CHSS system now operates. BHM also maintains the Area Resource File (ARF) system. ARF is a county-specific data system that contains a wide range of health and socioeconomic information that are compiled from secondary sources. The ARF system is used to assist both Federal and nongovernmental planning efforts.

The Health Services Administration (HSA) is responsible for Federal programs that, either directly or under grants or contracts, provide health care services to targeted population groups. Statutory language mandating collection of specific data apply, for the most part, to grantees or contractors operating health services delivery projects sponsored by HSA.

The Bureau of Medical Services (BMS) is responsible for health care services provided in PHS hospitals. It operates several data systems to provide planning and management information both for PHS hospitals and outpatient clinics. BMS also operates a data system that provides information about services delivered to eligible PHS beneficiaries in non-Federal contract programs. Finally, BMS is responsible for the emergency medical services program for which a uniform reporting system is not yet operational.

The Indian Health Service (IHS) provides comprehensive health services to American Indians and Alaskan Natives. Nine data collection systems managed by IHS supply information on services provided both by IHS hospitals, clinics, clinical laboratories, and by community, social, and mental health workers for planning, management, and evaluation purposes. IHS also administers sophisticated automated medical record systems in two of its service areas. These systems allow health team members to obtain detailed patient information immediately through computer terminals. Most data processing for the variety of data collection systems is done centrally at the IHS computer facility in Albuquerque, N. Mex.

The Bureau of Community Health Services (BCHS) oversees a number of categorical programs that provide medical services for underserved populations. In **1977,** BCHS instituted a management data system called the Bureau of Common Reporting Requirements (BCRR). This system collects uniform program data from all health services delivery projects, such as migrant or community health centers, that are funded by BCHS. Aggregate data are collected on patient characteristics, service utilization, staffing, and costs.

BCHS funds several other ongoing data collection projects, including one that collects data from a sample of clinics providing sickle cell anemia screening programs. BCHS and NCHS jointly administer another system that collects detailed clinical information from a sample of patients who visit family planning clinics. BCHS contracts with the Association of State and Territorial Health Officers for the operation of the National Public Health Program Reporting System (NPHPRS). This system is a summary report of State expenditures for public health activities by program categories. The qNPHPRS also provides data on State expenditures for activities under the Maternal and Child Health and Crippled Children's programs. Finally, BCHS also operates a data base that uses existing data sources, including NCHS, the United States Census, and the American Medical Association, to meet its legislative mandate to identify and designate medically underserved areas.

The National Institutes of Health (NIH) is composed of 11 research institutes dedicated to biomedical research on the cause, prevention, diagnosis, and treatment of disease. These institutes both conduct research in their own facilities and support research projects in universities, hospitals, and other non-Federal organizations.

Excluding laboratory research, NIH data collection projects are primarily epidemiological studies designed to trace the patterns of disease, to test specific hypotheses regarding the conditions and factors associated with significant disease rates, to identify risk factors in the population, and to determine the effectiveness of various diagnostic and treatment modalities. A small number of data collection projects focus on the incidence, prevalence, and related morbidity of specific diseases. NIH requires these data in an effort to establish research priorities for the study of diseases, to apportion research resources, and to determine population subgroups that may be at highest risk levels.

The National Cancer Institute (NCI), which is solely responsible for administering more than one-fifth of all Federal health research funds, conducts the largest data collection activities within NIH. Several of NCI'S more extensive epidemiological studies relate to screening for breast and cervical cancer. NCI also operates the Surveillance, Epidemiology, and End Results (SEER) data system to provide information for planning its research, control, and evaluation programs. Data are obtained in the SEER program from cancer registries that sample about 10 percent of the U.S. population. Data are available by site of cancer on cancer incidence, trends in therapy, and associated changes in patient survival.

Other NIH institutes that conduct numerous data activities are the National Heart, Lung and Blood Institute (NHLBI), the National Institute of Child Health and Human Development (NICHD) and the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS). NINCDS has conducted major national surveys to obtain data regarding the incidence and prevalence of brain tumors, head and spinal cord injury, multiple sclerosis, stroke, and epilepsy. NINCDS is now leading the efforts of several institutes to explore the feasibility of using a revised NCHS Hospital Discharge Survey to fulfill a substantial portion of their statistical needs.

Health Care Financing Administration

The Health Care Financing Administration (HCFA) was created as a part of an executive reorganization in March 1977 to unite public payment programs for health care under a single administration (3). * HCFA has three divisions, the Medicare Bureau, the Medicaid Bureau, and the Health Standards and Quality Bureau, each of which operates large, ongoing health data collection projects. HCFA'S staff office, the Office of Policy, Planning, and Research (OPPR), also operates a number of data projects.

The Medicare Bureau has primary responsibility for the Medicare program, which consists of two separate national health insurance programs for the aged and for certain other eligible categories of beneficiaries. The hospital insurance program, Part A of Medicare, reimburses medical facilities for a large portion of the costs of inpatient hospitalization and related services. The supplementary medical insuranc~ program, Part B of Medicare, pays for a range of services furnished by physicians or other health care professionals.

Program statistics for Medicare are collected as a byproduct of the claims review and payment process. Four basic data files—the enrollment file on eligible beneficiaries, the joint Medicare-Medicaid file on participating certified facilities, the Part A claims record, and the Part B payment record—form an extensive data base for the Medicare

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*Before IW7, the Medicare, Medicaid, and quality assurance programs were administered in three separate Federal agencies: the Social Security Administration (SSA), the Social and Rehabilitation Service (SRS), and the Health Services Administration (HSA).

program. Because beneficiaries and providers are identified in the data files, the Medicare statistical system is the only nationwide data system that, for example, permits linkage of hospital discharges with individual persons.

The diagnoses and surgical procedures contained in the Part A claims file are coded for 20 percent of the beneficiaries. The data from these bills are then matched to the enrollee and the provider data files so that use of medical services can be analyzed by both the demographic and geographic characteristics of the aged population and by the provider characteristics. The Medicare Provider Analysis and Review (MEDPAR), a separate statistical system, restructures these data for use by PSROS and local health planning agencies. For subsequent analytical use, MEDPAR generates statistical packages containing data on hospital utilization, inter-area facility comparisons, and utilization trends.

The Medicaid Bureau provides Federal financial support, through the Medicaid program, to State programs that pay for the medical care of low-income people. Each State defines income eligibility criteria for its own program; Federal financial support ranges from 50 to 83 percent of the State program’s cost.

In 1972, legislation was passed to encourage States to use an automated data system in their Medicaid programs, the Medicaid Management Information System (MMIS). MMIS, a generally designed system that can be adopted in whole, or in part, by States, is a claims processing and information retrieval system composed of six subsystems: recipient file, provider file, claims processing, reference file, surveillance and utilization review, and management and administrative reports. Federal guidelines specify the use of 114 standard data elements in the system, but only a small portion of these data are required to be forwarded to the Federal level. These Federal reporting requirements by States are called the Medicaid Minimum Data Set (MMDS). Because State Medicaid programs vary in their eligibility requirements, services covered, and payment methods, and, therefore, in program data requirements, reports produced from MMIS are not necessarily comparable from State to State.

The Health Standards and Quality Bureau (HSQB) certifies health care facilities for participation in the Medicare and Medicaid programs, and administers HCFA programs that monitor the quality of care provided to beneficiaries. HSQB administers a variety of data systems, including the Medicare/Medicaid Automated Certification System, the End-Stage Renal Disease Medical Information System (ESRD MIS), and the PSRO Management Information System (PMIS), that are designed to assess health care institutions and the health care services provided to Medicare and Medicaid recipients.

The Medicare/Medicaid Automated Certification System collects data on the number, type, characteristics, and geographic distribution of institutions that participate in Medicare and Medicaid. Hospitals, home health agencies, independent laboratories, skilled nursing facilities, and several other categories of providers are included in the data base.

The ESRD MIS assesses the appropriateness of treatment and quality of care given ESRD patients. Data are collected on medical support and treatment processes and on patient demographic characteristics, diagnoses, and outcomes. All ESRD patients whose treatments and rehabilitation costs are reimbursed by Medicare are included in the system.

Under the PSRO program, local physician-controlled organizations contract with HCFA to review the quality and appropriateness of medical care services provided to Medicare, Medicaid, and Maternal and Child Health program participants. The PMIS, the national PSRO data system, collects a minimum set of hospital discharge data that describe certain characteristics of every patient covered under a Federal payment program. With personal identifiers deleted, these data are forwarded to the Federal Government, along with summary information about the operation, the review process, and the costs of each PSRO. The data are used at the Federal level for evaluating the management and effectiveness of the PSRO program. Local PSROS use the data to generate profiles on patients, practitioners, and institutions. These profiles serve as an analytical base for developing standards for medical care. The PMIS data set requirements are established by Federal guidelines; individual PSROS may collect information that is not federally mandated to meet locally defined needs.

The Office of Policy, Planning, and Research (OPPR), a HCFA staff office, operates an extensive research and demonstration program related to the administration and operation of Medicare and Medicaid, to experimental methods of reimbursement, and to models for national health insurance. Data are gathered that describe costs, benefits, and operations of hospitals and skilled nursing facilities, uniform hospital accounting systems, physicians' practices and fees, and long-term care facilities. OPPR also analyzes data collected in the Medicare program.

Social Security Administration

The Social Security Administration (SSA) manages the Disability Insurance Trust Fund. The fund is used for paying monthly cash benefits to disabled workers who qualify as beneficiaries and their dependents. It also provides rehabilitation services to the disabled. Since 1937, SSA has maintained all employee records submitted by each company covered by the fund. These records, secured on microfilm, contain, at a minimum, the name and social security number of each employee and specific information regarding benefit computation and actions related to employee entitlement. SSA publishes annual statistical supplements and periodically prepares detailed analyses in its special report series. These reports are based on a sample of disability records and present data depicting the basic characteristics of individuals who apply for disability benefits. Several reports regarding specific disease entities have been published in this series. Characteristics of workers disabled by diabetes, emphysema, heart disease, cancer, and accidents, as well as mental illness, have been presented.

DATA COLLECTION ACTIVITIES OF OTHER FEDERAL AGENCIES AND DEPARTMENTS

The U.S. Department of Agriculture (USDA) is responsible for measuring and appraising trends and variations in U.S. food consumption. Since 1936, large-scale surveys have been conducted by USDA to study variations in household food consumption. In 1965, USDA expanded its efforts and initiated the Food Consumption Survey. This survey, measuring not only household but also individual food consumption, has been conducted twice. The information generated by the USDA surveys is used widely to evaluate the supply and use of food, per capita food consumption, and the nutritional status of the U.S. population. USDA also collects data relating to the purchase of food stamps and to participation in child nutrition programs.

The Consumer Product Safety Commission (cpsc''SC) is an independent agency emppowered to regulate certain products that may be hazardous. To identify the cause, frequency, and severity of injuries related to the use of particular products, CPSC operates the National Electronic Injury Surveillance System (NEISS). NEISS obtains data through a network of telecommunications terminals located in emergency rooms across the country. Another ongoing statistical system administered by CPSC collects data from poison control centers.

The Department of Defense (DOD) provides or funds health care services for over 9 million persons and operates more than 180 military hospitals for the benefit of active-duty personnel. The Assistant Secretary of Defense for Health Affairs is responsible for overall planning and coordination, but each service branch, Army, Navy, and Air Force, operates its own health services program. The General Accounting Office (GAO) evaluated the DOD health care program in 1976 and reported that over 400 health information systems were in various stages of development or operation within the Department (11). The Tri-Service Medical Information System (TRIMIS) program was established by DOD in 197’4 to improve the effectiveness and economy of DOD’s health care services through the use of computer technologies. At present, prototypic systems are being evaluated by TRIMIS before systemwide implementation takes place.

In addition, DOD periodically conducts special studies, including those that examine the health education needs of the military services, the perceived value of health care used by beneficiaries, and the feasibility of peer review for assuring quality of health service delivery. DOD also operates the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS). CHAMPUS, similar to private medical insurance programs, reimburses dependents of active duty personnel, retired members of the armed services, and other eligible beneficiaries for private fee-for-service health care. DOD is developing the CHAMPUS Management Information System (CMIS) to provide information for programmatic needs. A major element of CMIS is a computer file of all eligible beneficiaries; the system will also contain files on providers, claims processing, utilization review, and management and administrative reporting.

The Environmental Protection Agency (EPA) is charged with the regulation of environmental pollutants. EPA recently completed the Community Health Environmental Surveillance Studies System. This system used large-scale epidemiological methods to monitor the health of people in areas of high concentrations of air pollutants. EPA also conducts a small ongoing project, the National Human Monitoring Program, that collects and analyzes human blood, urine, and adipose (fatty) tissues for residues of regulated pesticides.

The Department of Labor (DOL) operates, through the Bureau of Labor Statistics (BLS), the Occupational Safety and Health Survey, an annual Federal/State cooperative survey that records the incidence and severity of occupation-related injuries and illnesses. The survey relies upon employers and employees to identify work-related illnesses. Because of the long latency period of many diseases, however, illness rates are inevitably underreported in this survey. BLS also conducts occupational employment surveys that sample specific categories of health manpower. The Mining Enforcement and Safety Administration (MESA), also in DOL, produces mine injury data and data on black and brown lung diseases.

The Department of Transportation (DOT) operates the Fatal Accident Reporting System (FARS) through its National Highway Traffic Safety Administration (NHTSA). This system provides annual data on all fatal motor vehicle accidents in the United States. FARS, fully automated and operational for more than a year, gathers information from sources maintained by States. The National Accident Reporting System (NARS), now being developed by NHTSA, will provide information on the rate of nonfatal motor vehicle accidents. NARS will be supplemented by the National Accident Sampling System, which will provide detailed information on a sample of accidents.

The Veterans Administration (VA), an independent Federal agency, operates the largest centrally directed hospital and clinic system in the United States. Its Department of Medicine and Surgery conducts a number of medical research and other special studies. The VA also operates several major automated information systems. The Automated Management Information System (AMIS), for example, provides information on VA hospitals for central planning and management purposes. Aggregate data are collected on admissions, the provision of services, and other categories of hospital operations. The Patient Treatment File (PTF) collects discharge data on all VA beneficiaries treated in hospitals, nursing homes, or domiciliary care facilities. PTF provides information on the use of the health care system and on patient diagnoses, surgical procedures, and other characteristics. A separate system gathers data on a sample of patients receiving outpatient care provided by VA facilities. The Personnel Accounting Integrated Data (PAID) system contains data on all VA personnel, including health professionals.