Appendixes

System/organization	Purpose and focus of data	Method of data collection	Population/locatlorr/time coverage	Statistics generated
Basic Vital Statistics				
NCHS	To provide uniform data on births, infant deaths, fetal deaths, birth weights, gestation	Birth and death registration in States 100 percent registration of all births and deaths in the country	Total United States since 1933 registration for all locations on an ongoing basis	Frequency of deaths by cause and fetal death Frequency of death
National Health Interview Survey				
NCHS	To provide data on acute and chronic illness prevalence among noninstiutionalized persons	Morbidity Survey-Multistage probability sample of standard geographic primary sampling units census enumeration districts and households Interviews conducted in households	120,000 civilian noninstitutionalized individuals throughout the United States covered each year since 1957 Data collected weekly throughout the year	Estimated frequency of physician visits and hospitalization Prevalence of chronic conditions Incidence of acute condition Morbidity associated with acute conditions
National Health and Nutrition Examination Survey (NHANES)				
NCHS	To provide data on health status and physiological measures of noninstitutionalized persons	Morbidity Health Survey—Multistage, highly clustered probability sample of persons stratified by geographic region and population density grouping Primary sampling unit is the same as for National Health Interview Survey Data collected by interview physician examination measurement and laboratory testing	Two cycles of NHANES have been conducted on the noninstitutionallized U S cwdtan population, Cycle (1971-74, Cycle I augmentation 1974.75, Cycle II 1976-79 A special survey of HIspanics is scheduled to begin In 1982	Morbidity measures Distribution of physiologic variables Prevalence of chronic conditions
National Hospital Discharge Survey				
NCHS	To provide medical diagnosis and surgical data on patients discharged from non-Federal short-slay hospitals	Hospital Utilization and Morbidity Survey-Two-stage cluster probability sample Hospital selection stratified by bed size region, and ownership Systematic sample of discharged patients	Since 1964, over 400 hospitals surveyed per year throughout the United States	Estimated frequency of specific diagnoses and surgical procedures by patient and hospital characteristics
National Death Index				
NCHS	To provide possible fact of death the death certificate number, and State of death	Registry of all death records in the United States transmitted by the States or other death registration areas	information for all States beginning in 1979 Updated annually thereafter	No statistics generated Computer searches used to assist researchers to determine whether persons m their studies may have died
National Natality Survey				
NCHS	To provide in-depth data on newborns and maternal health Prenatal and postnatal care, infant health, medical aspects of pregnancy, labor, and delivery	Followback survey Probability sample of 1 In 425 live births drawn from birth certificates	54 birth registration areas span the United States Natality surveys done on records of 1963-69 and 1972 1980 survey is currently underway	Demographic statistics of parents Frequency of radiologic procedures (1963) Factors associated with maternal and infant health
National Fetal Mortality survey				
NCHS	To provide data on the health of women who have stillbirths Prenatal and postnatal care medical aspects of pregnancy labor, and delivery	Followback survey Probability sample of two in five fetal death certificates	1980 survey, covering 52 birth registration areas is currently underway	Parental occupation Fact of maternal radiologic exposure Recent pesticides and insecticide exposure
National Ambulatory Medical Care Survey (NAMCS)				
NCHS	To provide data on use of office-based physicians	Morbidity Survey—Multistage probability sample of non-Federal physicians in office-based practice A systematic sample of results during a year within physician offices	Since 1973, an annual cycle of NAMCS has been conducted on noninstitutionalized visits to non-Federal physicians in the 48 contiguous United Stales	Frequency of visits by diagnosis Visit rates to physcians by age race sex and type of physician
National Disease Surveillance Program				
CDC	To examine disease and trends of 45 specific conditions, to identify regional problems, and to evaluate the effectiveness of control measures	Reporting System—Through epidemiology and laboratory Offices of State health departments Supplemented by information from epidemic investigations or outside sources such as NCHS	State county and city health authority areas throughout the United States	Incidence of 45 specific disease conditions

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Birth Defects Monitoring System CDC	To provide data on type and incidence of birth defects	Reporting System—Self-selected sample of hospitals Commission on Professional Hospital Activities (CPHA) hospitals with obstetric units are requested to participate. Report aggregate data on birth defects	Includes approximately one-third of all U S births Quarterly reporting began in 1970	Incidence of birth defects
Hepatic Angiosarcoma Surveillance Finding Effort CDC	To understand relationship between angle. sarcoma with health history and risk factors	National case findmg effort.	167 cases found, between 1964 and 1974	Incidence, risk factors
Smokey Nuclear Test Cohort Study CDC	To understand relationship between cancer, particularly leukemla, and nuclear test exposure	Complete followup of all film badge holders	Department of Defense workers at Smokey Nuclear Test Site m 1957 who worked 1 week prior to or after nuclear explosion and has possible exposure	Incidence and mortality data
Alcoholism Program Monitoring System NIAAA (ADAM HA)	To provide data to plan, manage and evaluate alcoholism	N/A	Programs funded by NIAAA	Data on clients, services, and costs
Client-Oriented Data Aquisition Process (COOAP) NIDA (ADAM HA)	To provide data on federally supported drug abuse and rehabilitation programs	Required reporting system	Collection at time of admission to, and discharge from, treatment programs	Client-related data
National Drug Abuse Treatment Utilization Survey NIDA (ADAMHA)	To provide data on nationwide resources devoted to drug abuse treatment, their use, and their dlstribution	Systematic survey, participation voluntary	Annually—nationwide	Use and distributuion of resources for drug abuse treatment
Drug Abuse Warning Network (DAWN) NIDA (ADAMHA)/DEA	To provide data on drug-related deaths, medical emergencies, and psychological crises	Voluntary reporting system	Participating emergency rooms, medical coroners, crisis intervention centers	Mortality and morbldity incidence
Adverse Drug Reaction Spontaneous Reporting System FDA	To provide for reporting of adverse effects of pharmaceutical products Fact of death, health outcome after reaction. concomitant diseases	Reporting system—Drug manufacturers hospitals, health care practioners file reports	Since 1968, 167,000 reports have been filed across the United States	Types of reactions by drug
Poisoning Control Case Registry FDA	To provide registration of acute poisoning incidents Signs and symptoms of poisioning, required medical intervention	Registry—Volunfary reporting of all contracts with 400 poison control centers	Since 1971, 1 2 million records of incidents have been placed in this system from across the United States	FDA use only
Registry of Tissue Reactions to Drugs FDA/Armed Forces Instltution of Pathology under auspices of Unlversities Associated for Research m Education and Pathology, Inc	To provide historical, clincal, laboratory, and morphological findings of adverse drug reactions	Reglsfry—Medical facilities reporting system	3,753 cases from 37 States since 1966	Quarterly reports of individual cases as to cause, basic disease, part of the body affected, and suspected drug(s)
Registry of Dermatological Reactions to Drugs FDA/National Academy of Dermatology	To improve the reporting of drug-caused skin reactions, and to test the feasibility of using a specialty society m medicine as the focal point for collecting drug experience data	Registry—24-hour loll-free telephone re-. porting system	National coverage, 3-year study starting in December 1980	Incidence data

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National Registry for Drug-Induced Ocular Side Effects				
FDA	To provide better Information on ocular side effects of drugs	Registry-Cases are reported primarily by opthamologists	National—700 cases reported between 1977 and April 1978	Quarterly and annual reports on individual drugs and effects.
Registry of Adverse Reactions to Contrast Media				
FDA/international Society of Radiology	To provide greater detail to the current study of adverse reactions to intravascular contrast media	Prospective registry	30 teaching hospitals m the United States Canada, and Europe 5,546 patients recorded with reactions out of 112,003 cases time period not reported	Incidence rates by types of examination and by types of patient reaction.
Nationwide Evaluation of X-Ray Trends (NEXT)				
Bureau of Radiological Health (FDA)	To detect and evaluate the extent of the population's exposure to X-rays used in medical and dental examinations	Systematic sample for participating States	Hospitals, private offices, and clinics	Incidence rates
Medically Oriented Data System (MOOS)				
Bureau of Medical Devices (FDA)	To provide an estimate of the frequency of use of various drugs, devices, and procedures as well as the frequency of adverse events following from such use	Systematic sample from participating hos0-pitals	Since September 1974 since 1977 has been a sample of 26 U S short-term hospitals	Incidence rate
Registry for Implanted Artificial Cardiac Pacamakers				
FDA	To provide data on new implant cardiac pacemakers, replacements, and intercurrent procedures	Registry of three medical center experiences	Medical Centers at University of Southern California, Montefiore Hospital, and Newark Beth Israel from July 1, 197410 Dec. 31, 1979, 5,070 registered pacemakers overall	Use patterns Morbidity and mortality rates
Surveillance, Epidemiology, and End Results Program (SEER)				
NCI (NIH)	To measure type and site of cancer incidence and survival m the United States, extent of disease, annual vital status	Morbidity survey-Sample of persons diagnosed with cancer 10 SEER locations chosen for contractual reasons, all cases of cancer m SEER area sampled	5 entire States and 5 metropolitan areas have been surveyed on an ongoing basis since 1973 Some of these locations surveyed m earlier NCI cancer surveys Population in these locations constitute 10 percent of U S total	Survival rates Incidence of cancer by site of cancer, geographic area race, and sex
Framingham Heart Study				
NHLBI (NIH)	To understand relationship between personal Characteristics, physiologic measures, physical signs and heart disease, cause of death	Prospective study —Representative sample of 1940 Framingham Population Follow. up of offspring of initial sample.	Followup of 5,209 persons m initial cohort ages, 29 to 62, in 1950, and 5,135 offspring, ages 16 to 52, in 1973 Follow-up began m 1940's and has continued up to present in Framingham, Mass	Cardiovascular and cancer incidence Risk statistics Mortality rates
Multirisk Factor Intervention Trial				
NHLBI (NIH)	To understand relationship between risk factors and heart disease physiologic measures, physical signs and fact of death from heart disease	Intervention trial—Two-stage sampling scheme. Nonprobability sample at 20 competitive research sites Identification of males at high risk of heart disease	Followup of 12,866 men. ages 35 to 57, from 1973 to 1976	Not yet available
Hypertension Detection Second Followup Program				
NHLBI (NIH)	Physiologic measures, physical signs, fact of cardiovascular disease and death recorded to understand relationship between drugs and control of hypertension	Intervention trial Two-stage sampling scheme Nonprobability sample of 14 communities. Identification of persons with elevated blood pressure in a set time period.	Since 1973, followup of 211,000 persons, ages 30 to 69	Morbidity and mortality rates

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Lipids Research Clinics Trial Study *NHLBI (NIH)*	Physiologic measures, physical signs and cause of death recorded to understand relationship between drugs and control of hyperlipidemia.	Intervention trial. Two-stage sampling scheme. Nonprobability sample of 12 lipid research clinics. Identification of persons known to be hyperlipidemic.	Since 1973, followup of 214,000 men, ages 35 to 69.	Not yet available.
Coronary Artery Surgical Study (CASS) *NHLBI (NIH)*	To provide data on patients undergoing coronary arteriography from which pool of available patients for a randomized clinical trial on coronary artery surgery could be drawn.	Registry.	Initiated in 1973; 24,188 patients entered into registry, from this 780 patients recruited for clinical trial.	Incidence rates.
Percutaneous Transluminal Coronary Angioplasty (PTCA) Registry *NHLBI (NIH)*	To collect and report incidence data and protocols of a new medical device/procedure.	Voluntary registry	International and ongoing; about 800 of 1200 procedures performed were reported by end of 1980.	Use patterns. Mortality and morbidity rates.
Multicenter databank networks for neurological disorders *NINCDS (NIH)*	To determine whether data collected routinely within the patient care process can benefit both clinical research and data management for 1) stroke patients and 2) traumatic coma victims	Each involves a prospective databank network at four Federally-funded university based clinical centers in United States	Implementation began in 1979.	Relationships between symptoms, stages of diseases, intervention, and outcome.
National Diabetes Data Group *NIAMDD (NIH)*	To estimate prevalance of diabetes on national scale, and monitor changes.	Statistical monitoring effort utilizing data pulled from existing files at NCHS	National.	Incidence patterns
Utah Genealogical Data Base *NIGMS (NIH)*	To estimate and predict medical and genetic patterns, and to analyze existing geneological patterns.	Geneology was constructed from family group sheets reconstituted by members of the Church of Jesus Christ of Latter-Day Saints	170,000 families in Utah.	Fertility, mortality, and other demographic data.
Medicare Claims File *HCFA*	To provide data on reimbursable claims from Medicare recipients; medical or surgical diagnosis; fact of death	Registry—Universal sample of claims for short-stay hospitalizations, nursing home claims, and physician bills are gathered. A 20-percent systematic sample of claims are coded for medical diagnosis	Since 1966, 20 million claims on people age 65 and over, those with chronic renal diseases, and those who meet the disability Act. Data entered on an ongoing basis.	Utilization statistics by diagnosis.
Medicaid Management Information System (MMIS) *HCFA*	To provide data on reimbursable claims from Medicaid recipients; medical and surgical diagnosis; fact of death.	State-based data collection systems; 27 States have certified MMIS programs, 19 others are planning or implementing an MMIS.	Since 1966, over 27 million claims for medical care of low-income people	Utilization statistics.
Professional Standards Review Organization (PSRO) Hospital Discharge Data Se *HCFA*	To provide data on patients reviewed by the PSRO review system; medical, surgical diagnosis and fact of death.	Registry—Universal coverage of patients reviewed by PSRO concurrent review process until 1977. A 20-percent systematic sample since 1977 using uniform hospital discharge survey forms.	Since 1975, PSRO's have provided data on Medicare and Medicaid discharges from 60 medical care regions.	Utilization statistics by diagnosis.

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Continuous Disability History Survey				
SSA	o provide data on applicants for disability benefits under Social Security Act title II Disability by diagnosiss for individuals	Survey of applicants for title II benefits Probability sample of claims stratified by State	Since 1967, 15,000 records have been placed in this file per year from throughout the United States	Frequency distribution of disabilty-related primary diagnosis by State
Leed File				
SSA	To provide Integrated occupational and **health status" information on social security number holders** Fact of disability and death	percent digital probability sample of social security numbers Integration of work history from Annual Employee Employer File with Summary Earning File File provides longitudinal information by person	Since 1957 **1-percent sample of wage** and salary workers covered under Social Security	Employment and earnings information from longitudinal analysis
Annual Disability Determmatlors/Social Security Income Extract				
SSA	To provide data on applicants for benefits under Social Security Act title XVI Disability by cause	Survey of Claimants for title XVI benefits 10-percent probability sample of claimants stratified by State with oversam pling of claims in small States or for children	Since 1975 100000 records have been placed in this file per year from throughout the United States	Frequency of disease and accident.related disability claims by State
Census of the Population				
Bureau of the Census (Commerce)	To provide demographic data on entire population	Enumeration of all residents	United States every 10 years	Demographic and socioeconomic characteristics
Annual Occupational Injuries and Illness Survey				
BLS	To provide data on work-related disease and injury Acute disease and acute injury by cause, with or without lost work days Fact of death	Morbidity Record Survey —Probability sam ple of employers under OSHA record-keeping stratified by Industry and establishment size	Since 1972, ongoing surveys of nearly all private sector Industries across the United States	Incidence of illness and injury by type of case per plant-hour worked
CHAMPUS (Civilian Health and Medical Program of the Uniformed Services)		Management Information System		
DOD	To provide reformation for eligible beneficiary programs Provider, claims, utilization and management data	Registry of program recipients	Dependents of active duty personnel, retired members of the armed forces, and others	Utilizatlon statistics
TRI-Service Medical Information Systems (TRIMIS) Program				
DOD	Clinical and adminstraive automated data processing for military medical treatment facilities	Patient registry	80 military medical facilities potentially about 89 million beneficiaries in DOD community	TRIM IS systems m operation include Pharmacy Formulary, Hypertension Management, Hospital Logistics and Automated Cardiac Catherization Laboratory
Compensation and Pension System				
VA	To provide data on recipients of VA benefits Disability by cause Fact of death in or out of service	Registry—Unwersal coverage of all veterans discharged with disability and receiving benefits	Since 1960, all veterans discharged who receive benefits far military-related disability	Level of compensation by diagnostic codes
Patient Treatment File				
VA	To provide data an VA system discharges Medical or surgical diagnoses	Registry --Universal sample Medical records abstracts for each hospital discharge	Since 1969, all VA systems patients discharged	Frequency of diagnostic category
Blue Cross-Blue Shield Systems				
Over 100 members of Blue Cross-Blue Shield Association	To provide information on beneficiaries for reimbursement and utilization review/ quality control generally	Registry of claims forms for reimburse. ment	More than 80 million people m the United States Six million of these are Federal workers (which for some research, approximates a national data set)	Utilization Statistics (data elements may vary from member to member)

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Computer-Stored Ambulatory Record System (COSTAR)				
Massachusetts General Hospital/NCHSR	To provide automated medical records and business support, quality assurance, patient followup reminders and selection of preferred therapies	Data bank of beneficiaries	Harvard Community Health Plan	Utilization Statistics
Problem-Orientation Medical Information Systems (PROMIS)				
Unversity of Vermont/ NCHSR	To restructure medical records and data to organize and help direct the process of clinical care and medical action	Computerized data bank of patient records entered by professional personnel	Available since 1977	Patient clinical and utilization statistics
Hospital Discharge Data Systems				
An estmated 18 to 20 private nonprofit hospital discharge abstract systems, including the Commission Professional and Hospital Activities (CPHA), and the Hospital Utilization Project (H UP)	To provide summary information about patients and their episodes of Illness in short-term hospitals	Registry—Pat!ent information for particpating hospitals ıs abstracted from medical records by hospital personnel after patients are discharged, according to a prescribed format	About half the hospitals m the United States, representing about 20 million discharges annually	Utilization and clinical Statistics
DES Vaginal Cancer Registry				
Or Arthur Herbst/ University of Chicago	To investigate the clinical, pathologic, and epidemiologic aspects of clear ceil adenocarcinomas occurring in the vagm+r and cervix of females born after 1940	Voluntary registry	International in scope, with 341 cases reported, established since 1971 Considered highly precise, i.e., has captured about 85 to 90 percent of DES universe	Mortality and morbidity data, clinical histories
Rhode Island Diabites Registry				
Rhode Island Department of Health	To provide information on young insulin dependent diabetics (Type I juvenile . diabetic)	Prospective 3-year recustry charts reviewed on weekly or biweekly basis, with individual physicians subsequently interviewed	Patients who are 1) insulin-dependent at 15 acute-care hospitals in the State, 2) under 30, and 3) residents of the State	Incidence, patient-care patterns
Pittsburgh Diabeties Registry				
N/A	To provide Information on the etiology of juvenile onset diabetes	Retrospective registry	Pittsburgh, Pa , metropolitan area covering a 12-year period	Incidence data
American Rheumatism Association Medical Information System (ARAMIS)				
Consortium of several medical groups centered at Stanford University Medical Center	To collect Patient information on a variety of rheumatic diseases among different patient populations	Six data banks at medical institutions	10,000 patients in system m the United States and Canada, extensive followup in some cases	Incidence rates, clinical patterns
Duke University Cardiovascular Data bank				
Duke University Medical Center/NCHSR	To provide onformation on patients with known or suspected Ischemlc heart disease and to describe outcomes of patients with various sets of attributes, patients findings, histories, outcomes	Computerized data bank	Over 6,000 Patients a! Duke University Medical Center since 1976	Incidence and clinical patterns
Databank on patients in coma for causes other than head injury				
New York Hospital-Cornell University Medical Center	To provide information on nontraumatic coma patients, allow future predictive power and clinical Improvement m treatment, symptoms, diagnoses, procedures. functional states, causes of death	Computerized data banks located in several medical centers m the United States and Great Britian	Accesses about 500 patients per year	Morbidity and mortality data, patterns of clinical practice

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Intensive Care Databank				
Massachusetts General Hospital	To collect Information and evaluate practices regarding intensive care units diagnoses, functional status, indication data, charges	Computerized data bank Patient records and subsequent Interviews were recorded and coded	2,305 patients admitted to one of the three intensive care units at Massachusetts General from July 1977 to July 1979	Morbidity and morality data patterns of clinical practice
SEARCH				
Rhode Island Health Services Research, Inc	To provide a neutral resource organization whose health information sources could service a diverse need of all the State s health providers and planners, census and vital statistics, planning and utilization data	Computerized data bases S!ate-wide cooperate reporting system 10 private not for-profit organization	State of Rhode Island since 1968	Vital statistic utilization rates facility and expenditure data
Drug Epidemiology Unit				
Boston University Medical Center	To study a broad range of problems concerning the clinical effects of drugs m humans, with particular emphasis on adverse effects, life-time histories of drug use, patients characteristics and diagnostic information	Case-control surveillance system in 11 medical centers nurse-monitors interview subjects	Established July 1976, over 10,000 individuals studied m United States and Canada	Drug incidence and utilization data
Pediatric Drug Surveillance Program				
Boston Children's Hospital Medical Center in collaboration with Drug Epidemiology Unit	To provide an estimate of the incidence of adverse reactions m hospitalized children	Case-control surveillance, nurse monitors collection of information	Established 1974, to date over 4500 pediatric patients from premature newborns to young adults	Drug Incidence and utilization data
Boston Collaborative Drug Surveillance Program (BCDSP)				
BCDSP/FDA	To provide some quantification of clinical efficacy and toxicity for prescribed drugs m specific types of patients.	Surveillance among hosptalized medical and surgical patients by specially trained monitors	Since July 1966 m over 40 hospitals and seven countries on nearly 100000 patients	Drug incidence and utilization rates Efficacy ratings of drugs used
Dunedin Program				
Dunedin, Florida Clinic	To screen participants over the age of 65 for medical disorders	Data from patient records and interviews were collected	Over 5,000 participants, an ambulatory geriatric population	Drug Incidence and utilization rates
Olmstead Country, Minnesota System				
Mayo Clinic and Olmstead Medical and Surgical Group	To provide a complete medical record and Information system for a circumscribed population for Clinical and followup care all contacts with the medical system are recorded	Computerized medical records	About 98 percent of Olmstead Country residents, medical records for population dating back to 1907	Incidence and utilization patterns
Seatte Group Health Cooperative System				
Seattle Group Health Cooperative	To develop comprehensive system tabulation on inpatient procedures and diagnoses, outpatient drug utilization enrollment features, and outcome measures	Centralized automated data bank	Over 270,000 members, 2 demographic base that resembles metropolitan Seattle, Wash	Incidence and utilization rates, mortality, morbidity data, patterns of clinical practice

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Health Services Research Center (Oregon Region) System				
Kaiser-Permanente Medical Care Program	To develop a computerized medical record for all center patients; extensive inpatient, outpatient, pharmacy and laboratory information.	Outpatient utilization records for a 5 percent sample of the Health Plan subscriber units and inpatient utilization records for 100 percent of hospital users.	Inpatient data over last 13 years.	Incidence and utilization rates; patterns of system and resource response.
Manitoba Health Services Commission Databank				
Province of Manitoba, Canada	To provide for payment and control on population coverage; admission and discharge, service, diagnosis, surgical, followup information.	Comprehensive computerized databank through claims forms and individual hospital files.	All individuals registered in Manitoba (regardless of where care is received).	Registration, hospitals, and medical data
Seattle Heart Watch				
Communitywide registry	Angiographic data for determining the antecedents of sudden cardiac death.	Registration of all patients having coronary angiography and left ventriculography for systems or signs of ischemic myocardial disease.	A total of 2,616 patients from three private and two university teaching hospitals in Seattle, Washington from 1969 through 1974.	Mortality and cardiovascular morbidity measures; 6-month interval followups.