Inventory of Data Sources for Estimating Health Care Costs in the United States

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Objective: To develop an inventory of data sources for estimating health care costs in the United States and provide information to aid researchers in identifying appropriate data sources for their specific research questions.

Methods: We identified data sources for estimating health care costs using 3 approaches: (1) a review of the 18 articles included in this supplement, (2) an evaluation of websites of federal government agencies, non profit foundations, and related societies that support health care research or provide health care services, and (3) a systematic review of the recently published literature. Descriptive information was abstracted from each data source, including sponsor, website, lowest level of data aggregation, type of data source, population included, cross-sectional or longitudinal data capture, source of diagnosis information, and cost of obtaining the data source. Details about the cost elements available in each data source were also abstracted.

Results: We identified 88 data sources that can be used to estimate health care costs in the United States. Most data sources were sponsored by government agencies, national or nationally representative, and cross-sectional. About 40% were surveys, followed by administrative or linked administrative data, fee or cost schedules, discharges, and other types of data. Diagnosis information was available in most data sources through procedure or diagnosis codes, self-report, registry, or chart review. Cost elements included inpatient hospitalizations (42.0%), physician and other outpatient services (45.5%), outpatient pharmacy or laboratory (28.4%), out-of-pocket (22.7%), patient time and other direct nonmedical costs (35.2%), and wages (13.6%). About half were freely available for downloading or available for a nominal fee, and the cost of obtaining the remaining data sources varied by the scope of the project.

Conclusions: Available data sources vary in population included, type of data source, scope, and accessibility, and have different strengths and weaknesses for specific research questions.

Key Words: health care costs, data sources, administrative data, linked data, survey, health economics

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Health care cost estimates are used to inform policy decisions on the setting of public and private budgets, structuring of insurance benefits and establishing reimbursement rates, and in cost-of-illness and cost-effectiveness analyses. In the United States, many sources of data are available for estimating health care use and costs. Prior reviews have identified some of these data sources[1,2] or summarized data sources used in cost-of-illness studies.[3,4] To build on these efforts, and aid analysts in the process of identifying and choosing data sources for estimating health care costs, we developed an inventory of data sources in the United States.

The majority of data sources commonly used to estimate health care costs in the United States were not originally developed for research purposes. Longitudinal information across the trajectory of illness is generally available only for the covered populations within discrete health insurance programs. National information is available from a variety of patient surveys and hospital discharge databases, but these data are generally cross-sectional, and may have small numbers of individuals with specific conditions. Several panel surveys collect information at multiple time points, but are of short duration or limited in clinical detail.[5,6] Because comprehensive longitudinal data for nationally representative populations across health insurance programs and without health insurance are largely unavailable, analysts must choose between different attributes of data sources for their specific study questions.

The choice of data source is important, because as illustrated in several articles in this issue, different data

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sources can produce different estimates of the cost of health care.[7,8] In addition, some existing data sources have rarely been used for estimating health care costs. For example, some costs, such as patient and caregiver time costs, are routinely excluded from cost-effectiveness analyses, even though they have long been recommended for inclusion,[9] often in the mistaken belief that these data are not available. In the following sections, we describe our approach to identifying data sources for estimating health care costs, provide a summary of data source attributes, and include a series of tables with detailed information about the attributes of each data source. This information can serve as a resource for researchers choosing data sources for estimating health care costs.

IDENTIFICATION OF DATA SOURCES FOR ESTIMATING HEALTH CARE COSTS

We identified data sources for estimating health care costs in the United States using 3 approaches: (1) a review of the 18 articles included in this supplement,[5,7,8,10–24] (2) an evaluation of websites of federal government agencies, nonprofit foundations, and related societies that support health care research or provide health care services, and (3) a systematic review of the recently published literature. Although health care utilization patterns from many data sources can be applied to standard fee schedules, we only considered data sources where direct medical or direct nonmedical health care costs are available or can be derived. We use the term "cost" to refer to payments, expenditures, reimbursements, charges, or prices.

Our review of federal government agency websites included the Agency for Healthcare Research and Quality, Bureau of Labor Statistics, the Centers for Disease Control (and the National Center for Health Statistics), the Centers for Medicare and Medicaid Services, the Department of Defense, the Federal Interagency Forum on Aging-Related Statistics, the Health Resources and Services Administration, the 27 individual Institutes and Centers of the National Institutes of Health, and the Veterans Health Administration. We also reviewed the websites of Academy Health, the Commonwealth Fund, the International Society for Pharmacoeconomics and Outcomes Research, the Kaiser Family Foundation, the Robert Wood Johnson Foundation, and the Research Data Assistance Center, a contractor to the Centers for Medicare and Medicaid Services that provides assistance to researchers interested in using Medicare or Medicaid data (http://www.resdac.umn.edu/).

To identify data sources from the published literature, we used Scopus, the largest abstract and citation database, including 15,000 peer-reviewed journals and 100% MEDLINE coverage (http://www.info.scopus.com/). We identified articles published in English between January 1990 and December 2007 that included the terms "cost," "economic," "expenditure," "charge," or "payment" in the title (N = 141,876), and used the search terms "data source" or "database" (N = 450,862 articles) and "healthcare" and ("cost" or "payment" or "charge") or "health care" and ("cost" or "payment" or "charge") for the full article (N = 37,946 articles). The combination of these searches yielded 539 articles.

The abstract for each article was reviewed to identify the data source(s) used to estimate health care costs, if possible. If the source could not be identified from the abstract, the entire article was reviewed. We excluded studies that met any of the following criteria: data source was from outside the United States, monetary estimates were not presented, data were not available after 1990, data were

TABLE 1. Characteristics of Data Sources for Estimating Direct Medical and Nonmedical Health Care Costs

	Data Sources	
	Number (N = 88)	%
Lowest level of data aggregation		
National	2	2.3
Hospital/provider	12	13.6
Service	22	25.0
Individual/patient	52	59.1
Sponsor*		
Government agency	60	68.2
Private (for profit and not-for profit)	34	38.6
University	4	4.5
Population		
National or nationally representative	64	72.7
Multistate	16	18.2
Other	8	9.1
Type of data source		
Survey	37	42.0
Administrative data or linked administrative data	25	28.4
Discharge	5	5.7
Fee or cost schedule	14	15.9
Other	7	8.0
Length of observation		
Cross-sectional (or single observation)	55	62.5
Longitudinal	33	37.5
Source of diagnosis information*		
Procedure, diagnosis or DRG codes	40	45.5
Self-report	18	20.5
Registry	6	6.8
Chart or medical review	6	6.8
Other	3	3.4
Not available	29	33.0
Cost elements*		
Institution or facility	5	5.7
Inpatient hospitalization	37	42.0
Physician and other outpatient	40	45.5
Outpatient pharmacy or laboratory	25	28.4
Out-of-pocket	20	22.7
Patient time and other direct nonmedical	31	35.2
Wages	12	13.6
Cost of data		
Freely available for downloading/less than $100	43	48.9
Cost varies with scope of project	45	51.1

*Percentages add to more than 100%.

TABLE 2. Hospital and Provider Level Data Sources Used to Estimate Direct Medical Health Care Costs

Data Source	Description	Diagnosis Information Available	Cost Elements		
			Institution or Facility	Inpatient Hospitalization	Wages/Payroll
American Hospital Association Annual Survey (AHA)	Annual survey of more than 6000 hospitals with information on organizational structure, facilities and services, utilization, managed care relationships, staffing, and expenses		√		√
American Hospital Directory (AHD)	Database of 6000 hospitals with information from both public and private sources including Medicare claims data, hospital cost reports, and other files obtained from the CMS	√, DRG codes	√	√	
Area Resource File (ARF)	Contains information on facilities, health professions, economic activity, and socioeconomic characteristics for each of the nation's counties. Hospital information includes overall expenditures and Medicare reimbursements		√		√
Community Health Workers (CHW) National Workforce Study	Survey of CHW employers in all 50 states and in-depth interviews of employers and CHWs in 4 states to make national and state workforce estimates. CHW wages are reported				√
Current Employment Statistics (CES)	Each month the CES program surveys about 150,000 businesses and government agencies to provide detailed industry data on employment, hours, and average hourly and weekly earnings of workers on nonfarm payrolls				√
Medical Group Management Association (MGMA), Physician Compensation and Production survey	Annual survey of MGMA membership of physicians, group practices, and specialties to obtain physician compensation and production data, including starting salaries by specialty and professional charges, gross charges, and total and physician work relative units				√
Medicare Cost Reports	Contains provider information such as facility characteristics, utilization data, cost and charges by cost center (total and for Medicare), Medicare settlement data, and financial statement data. Includes cost reports for hospital, skilled nursing facility, home health agency, renal facility, and hospice		√		
National Association of Psychiatric Health Systems (NAPHS) Annual Survey	Survey includes information on behavioral health care delivery, including trend analysis in hospitals and residential treatment centers and cost items such as average net revenue per inpatient hospitalization and total net revenue by residential treatment center		√	√	
National Compensation Survey (NCS)	Comprehensive measures of occupational earnings and wage, employment cost trends, and detailed benefit provisions based on visits to establishments. Detailed occupational earnings are available for metropolitan and nonmetropolitan areas, and nationally				√
National Sample Survey of Registered Nurses (NSSRN)	Survey of registered nurses in the workforce about education and training, current and recent workforce participation, and income				√
Occupational Employment Statistics (OES) Survey	Employment and wage estimates for over 800 occupations, including mean and median hourly wages for physicians and surgeons, registered nurses, and other health professionals. Available nationally, for states, and metropolitan areas				√
Quarterly Census of Employment and Wages (QCEW)	Quarterly count of employment and wages reported by employers covering 98% of US jobs. Files include data on the number of establishments, monthly employment, and quarterly wages, by industry, county, and sector				√

TABLE 3. Service Level Data Sources Used to Estimate Direct Medical Health Care Costs

Data Source	Description	Diagnosis Information Available	Cost Elements		
			Inpatient Hospitalization	Outpatient Services	Pharmacy and Equipment
Alere databases	Discharge planning tool	√, DRG codes	√		
Centers for Disease Control and Prevention (CDC) Vaccine Price List	Provides current vaccine contract prices and private sector prices reported by vaccine manufacturers				√
Chain Pharmacy Industry Profile	Contains statistics on operational performance of retail pharmacies and average prescription prices by state and source of payment				√
First DataBank National Drug Data File (NDDF)	Contains descriptive and pricing information for medications approved by the FDA, and commonly-used over-the-counter and alternative therapy agents				√
Healthcare Costs and Utilization Program (HCUP)-Nationwide Inpatient Sample (NIS)	The largest all-payer inpatient care database with all discharge data from sampled hospitals. Includes diagnoses, procedures, admission and discharge status, patient demographics, expected payment source, total charges, length of stay, and hospital characteristics	√, procedure or diagnosis codes	√		
HCUP Kids' Inpatient Database (KID)	The only all-payer inpatient care database for children. Includes diagnoses, procedures, admission and discharge status, patient demographics, expected payment source, total charges, length of stay, and hospital characteristics	√, procedure or diagnosis codes	√		
HCUP State Ambulatory Surgery Databases (SASD)	Contains ambulatory surgery encounter abstracts in participating states. All databases include abstracts from hospital-affiliated ambulatory surgery sites and some contain the universe of ambulatory surgery abstracts for that state. Includes diagnoses, procedures, discharge status, patient demographics, expected payment source, total charges, and hospital identifiers	√, procedure or diagnosis codes		√	
HCUP State Emergency Department Databases (SEDD)	Captures discharge information on all emergency department visits in participating states that do not result in an admission. Includes diagnoses, procedures, patient demographics, expected payment source, total charges, and hospital identifiers	√, procedure or diagnosis codes		√	
HCUP State Inpatient Databases (SID)	Contains the universe of inpatient discharge abstracts in participating states, about 90% of all US community hospital discharges. Includes diagnoses, procedures, admission and discharge status, patient demographics, expected payment source, total charges, length of stay, and hospital characteristics	√, procedure or diagnosis codes	√		
Medicare Ambulance Fee Schedule	All ambulance services, including volunteer, municipal, private, and institutional providers, ie, hospitals, critical access hospitals, and skilled nursing facilities			√	
Medicare Ambulatory Payment Classifications (APC)	Part of the OPPS. Services in each APC are similar clinically and in terms of the resources they require. Depending on the services provided, hospitals may be paid for more than one APC for an encounter			√	
Medicare Clinical Laboratory Fee Schedule	Covers outpatient clinical laboratory services which are paid based on the lesser of the amount billed, the local fee for a geographic area, or a national limit			√	
Medicare Diagnosis Related Group (DRG) Fee Schedule	Developed as part of the Medicare prospective payment system to classify hospital cases into one of approximately 500 groups, expected to have similar hospital resource use. DRGs are assigned by a "grouper" program based on ICD diagnoses, procedures, age, sex, and the presence of complications or comorbidities	√, DRG codes	√		
Medicare Durable Medical Equipment, Prosthetics/Orthotics Supplies Fee Schedule	Medicare payment for durable medical equipment, prosthetics and orthotics, parenteral and enteral nutrition, surgical dressings, and therapeutic shoes and inserts				√
Medicare Hospital Outpatient Prospective Payment System (OPPS) File	Medicare file contains select claim level data and is derived from hospital outpatient prospective payment system claims	√, procedure or diagnosis codes		√	

(*Continued*)

TABLE 3. (*Continued*)

Data Source	Description	Diagnosis Information Available	Cost Elements		
			Inpatient Hospitalization	Outpatient Services	Pharmacy and Equipment
Medicare Physician Fee Schedule	Medicare payments for physician and nonphysician services developed with estimates of total practice expenses that physicians in each specialty incur and of resources required to perform each of the individual services in each specialty		√	√	
Medispan Drug Database	Databases contain drug product and pricing information and clinical decision support databases that identify drug conflicts				√
Physicians' Desk Reference-Red Book	Provides prices on prescription drugs, OTC items and reimbursable medical supplies, including average wholesale prices, direct prices, and federal upper limit prices for prescription drugs; and suggested retail prices for OTC products				√
State Medicaid prescription reimbursement information	Reports reimbursement methodologies, dispensing fees, and co-payment amounts utilized by state Medicaid programs				√
WisdomKing.com	Lists prices for physical therapy supplies, physical therapy equipment, and rehabilitation products				√

from a single institution or a clinical trial and unlikely to be widely available to other investigators, or the study was only available in the form of a published abstract or dissertation (N = 266). Because electronic searches may not identify all relevant studies,[25] we also evaluated all reviews (N = 107) to identify data sources used in the underlying research studies. The underlying research studies were evaluated further and the same eligibility criteria were applied. From the 3 search strategies, we identified a total of 88 data sources with sufficient information to abstract key data elements.

Because our goal was to provide information for analysts interested in using these data sources, we made extensive efforts to identify as many data sources and data elements as possible. Some data sources mentioned in the literature review could not be located. Others have been discontinued or merged with other data sources. In situations where we could not abstract the information about the population and cost elements from the data source website, we followed up with the listed contact for additional information. Despite these efforts, we did not have sufficient information about several data sources to include them in this inventory.

ABSTRACTION OF DATA SOURCE ATTRIBUTES

Information about each data source was abstracted using a standardized format. We abstracted descriptive information about the data source, including the sponsoring agency or organization (government, private, university), website for the data source, lowest level of data aggregation (hospital or provider, service, and individual or patient), and type of data source (survey, administrative or linked administrative data, discharge, fee or cost schedule).

We also abstracted information about the eligible or covered population, whether the data were nationally representative, whether they were cross-sectional or longitudinal (including repeated cross-sections or panels), and the source of diagnosis information (procedure or diagnosis codes, self-report, chart or medical record, registry, not available). Cost elements abstracted were the types of services or resources for which cost data were collected, including institution or facility (eg, hospital or freestanding clinic), inpatient hospitalization, physician and other outpatient, outpatient pharmacy or laboratory, out-of-pocket, wages, patient time, and other direct nonmedical (eg, disability days). The cost of obtaining the data source was categorized as either (1) freely available for download/less than $100 or (2) cost depends on scope of project. We did not gather information about data completeness or quality.

ATTRIBUTES OF DATA SOURCES FOR ESTIMATING HEALTH CARE COSTS

Descriptive characteristics of the data sources we identified are summarized in Table 1 and listed for individual data sources in the remaining Tables. The lowest level of data aggregation for most sources was the individual or patient-level, followed by the service level, and hospital, provider, or institution level. Two data sources were aggregated at the

TABLE 4. Individual or Patient Level Data Sources Used to Estimate Direct Medical Health Care Costs: Surveys

Data Source	Population	Diagnosis Information Available	Cost Elements				
			Inpatient Hospitalization	Physician and Other Outpatient Services	Outpatient Pharmacy	Out-of-Pocket	Nonmedical
Alcohol and Drug Services Study	Nationally representative sample of substance abuse treatment facilities and clients in the US. Data were collected through telephone interviews, records reviews, and follow-up personal interviews	√, procedure or diagnosis codes	√	√			√
Community Tracking Survey (Household Component)	Nationally representative sample of the civilian, noninstitutionalized population. The survey is conducted by telephone					√	√
Consumer Expenditure Survey (CES)	Nationally representative sample of civilian, noninstitutionalized consumer units (eg, households). Information is obtained through a quarterly personal interview and weekly diaries	√, self-report				√	
Consumerism in Health Survey	Sample of privately insured adults ages 21–64. Information was obtained through an internet survey					√	
Current Population Survey (CPS)	Nationally representative sample of the civilian, noninstitutionalized population over 16 yr of age. Data are collected by personal and telephone interviews						√
HIVnet	Data from 12 medical practices located across the US with 14,000 HIV patients	√, procedure or diagnosis codes	√	√			
Kaiser Women's Health Study	Nationally representative sample of civilian, noninstitutionalized women ages 18 to 64. The survey was conducted via telephone interview	√, self-report				√	
Medical Expenditure Panel Survey, Household and Provider Components (MEPS)	Nationally representative sample of the US noninstitutionalized population. Survey data were collected through personal interviews. MEPS also collects data from medical providers which supplements and/or replaces information received from the household respondents about the health care that was provided to the sampled household members	√, self-report and chart or medical record	√	√	√	√	√
National Health and Wellness Survey	Representative of the general population of adults aged 18+ in the US, European Union, and Asia		√	√	√	√	√
National Health Interview Survey (NHIS) (Core)	Nationally representative sample of US civilian noninstitutionalized population. Data are collected via a personal household interview					√	
National Home and Hospice Care Survey (NHHCS)	Nationally representative sample of the US civilian, noninstitutionalized population obtaining services from a home or hospice care agency licensed or certified by Medicare or Medicaid. Data are collected through personal interviews with administrators and staff	√, chart or medical record		√			√

(*Continued*)

TABLE 4. (*Continued*)

Data Source	Population	Diagnosis Information Available	Cost Elements				
			Inpatient Hospitalization	Physician and Other Outpatient Services	Outpatient Pharmacy	Out-of-Pocket	Nonmedical
National Long Term Care Survey (NLTCS)	Nationally representative sample of the elderly population (65 yr or older) enrolled in Medicare, who are living in the community or institutions. Data are collected through personal interviews	√, proxy report	√	√			√
National Mortality Followback Survey (NMFS)	National sample of death certificates for individuals aged 15 yr and over who were residing and died in the US. Survey is completed by next of kin or another person familiar with the decedent's life history	√, proxy report				√	√
National Nursing Home Survey (NNHS)	Nationally representative sample of the US civilian, noninstitutionalized population obtaining services from a nursing home certified by Medicare or Medicaid, or having a state license to operate as a nursing home. Data is obtained through interviews	√, chart or medical record		√		√	√
National Survey of Ambulatory Surgery (NSAS)	Survey of patients scheduled for surgical and nonsurgical procedures performed in hospital-based and freestanding ambulatory surgery centers	√, chart or medical record		√			√
National Survey of America's Families (NSAF)	Nationally representative sample of the civilian, noninstitutionalized population under the age of 65. The survey is conducted by telephone interviews					√	
Panel Study of Income Dynamics (PSID)	Nationally representative sample of civilian, noninstitutionalized individuals, and the family units in which they reside. Information was obtained via telephone interviews with computer-based instruments	√, self-report				√	√
Survey of Income and Program Participation (SIPP)	Nationally representative sample of households in the US civilian, noninstitutionalized population. Information is obtained via in-person interviews					√	√

TABLE 5. Individual Level Data Sources Used to Estimate Direct Medical Health Care Costs: Administrative Data, and Registries and Surveys Linked to Administrative Data

			Cost Elements				
Data Source	**Population**	**Diagnosis Information Available**	**Inpatient Hospitalization**	**Physician and Other Outpatient Services**	**Outpatient Pharmacy**	**Out-of-Pocket**	**Nonmedical**
Alere databases	Information management system with administrative data	√, procedure or diagnosis codes	√	√	√		
Blue Cross/Blue Shield	Enrollees in 39 independent and locally operated health plans	√, procedure or diagnosis codes	√	√	√		
Cancer Research Network (CRN)*	Cancer and noncancer patients receiving care in a consortium of 14 nonprofit research centers in integrated health care delivery organizations across the nation	√, registry (cancer) and procedure or diagnosis codes	√	√	√		
Health and Retirement Survey (HRS)-Medicare†	Total civilian noninstitutionalized population age 50 and older who were enrolled in Medicare and provided personal identification data	√, self-report and procedure or diagnosis codes	√	√	‡		
Health Maintenance Organization Research Network (HMORN)	Patients receiving care from any of 15 HMOs with formal recognized research capacities	√, procedure or diagnosis codes	√	√	√		
Human Capital Management Services (HCMS)	Individuals enrolled in employer-sponsored insurance. Also includes information on sick leave, disability, and productivity	√, procedure or diagnosis codes	√	√	√	√	√
IMS health plan data	Enrollees in 97 health plans nationwide	√, procedure or diagnosis codes	√	√	√	√	
Ingenix	Enrollees in large geographically diverse health insurance plan	√, procedure or diagnosis codes	√	√	√		
MarketScan databases	Large national claims and encounters data for individuals enrolled in employer-sponsored commercially insured and Medicare supplemental insurance. Subsets of patients may be linked to short-term disability and absenteeism data	√, procedure or diagnosis codes	√	√	√	√	√
Medicaid	Enrollees in state-based program available only to medically needy, categorically needy or special groups. Eligibility varies state to state and group to group	√, procedure or diagnosis codes	√	√	√		
Medicare	Beneficiaries in Medicare program with fee-for-service coverage aged ≥65 yr, <65 yr with certain disabilities, or all ages with End-Stage Renal Disease (ESRD)	√, procedure or diagnosis codes	√	√	‡		
Medicare Current Beneficiary Survey (MCBS)†	Nationally representative sample of aged, disabled, and institutionalized Medicare beneficiaries	√, self-report, chart, and procedure or diagnosis codes	√	√	√‡	√	√
MediQual/Cardinal Health Atlas System	Information management system with clinical and administrative data	√, procedure or diagnosis codes	√	√			
MedMining, a Geisinger Health System business	Patients of all ages in an integrated, health care system spanning 40 counties in Pennsylvania	√, procedure or diagnosis codes	√	√	√	√	√
National Health and Nutrition Examination Survey (NHANES) – Medicare†	National sample of civilian noninstitutionalized participants in NHANES who were enrolled in Medicare and provided personal identification data to NCHS	√, examination and procedure or diagnosis codes	√	√	‡		√

(*Continued*)

TABLE 5. (*Continued*)

Data Source	Population	Diagnosis Information Available	Cost Elements				
			Inpatient Hospitalization	Physician and Other Outpatient Services	Outpatient Pharmacy	Out-of-Pocket	Nonmedical
National Health Interview Survey (NHIS)-Medicare†	National sample of civilian noninstitutionalized respondents to the NHIS who were enrolled in Medicare and provided personal identification data to NCHS	√, self-report and procedure or diagnosis codes	√	√	‡		√
National Long Term Care Survey (NLTCS)–Medicare†	Nationally representative sample of the elderly population ≥65 yr enrolled in Medicare, living in the community or institutions. Data are collected through personal interviews	√, self-report and procedure or diagnosis codes	√	√	‡		√
New Beneficiary Data System-Medicare†	Sample of Social Security beneficiaries who were retired or disabled workers, or other aged (ie, wife or widow) with 10-yr follow-up	√, procedure or diagnosis codes	√	√	‡		
PharMetrics (Integrated Medical and Pharmaceutical Database)	Patients from over 90 health plans across the US with multiple product types (eg, HMO, PPO), payor types (eg, commercial, self-pay), provider specialty, and start and stop dates for plan enrollment.	√, procedure or diagnosis codes	√	√	√	√	
Premier Perspective Database	Provides drug utilization, inpatient discharges, and hospital outpatient visits from acute care facilities, ambulatory surgery centers and clinics	√, procedure or diagnosis codes	√	√	√	√	
Surveillance, Epidemiology and End-Results (SEER)–Medicare*	Cancer patients and noncancer patients in a SEER region who are enrolled in Medicare fee-for-service ≥65 yr, <65 yr with certain disabilities, or any age with End-Stage Renal Disease (ESRD)	√, registry (cancer) and procedure or diagnosis codes	√	√	†		
The Second Longitudinal Study of Aging (LSOA II)–Medicare†	Total civilian noninstitutionalized population ≥70 yr in LSOA enrolled in Medicare and provided personal identification data to NCHS	√, self-report and procedure or diagnosis codes	√	√	‡		
United Healthcare	Enrollees in large health insurance company	√, procedure or diagnosis codes	√	√	√		
United States Renal Data System (USRDS)*	All end-stage renal disease (ESRD) patients eligible for Medicare. Includes data from CMS with other databases	√, registry (ESRD) and procedure or diagnosis codes	√	√	‡		
Veterans Affairs (VA) National Prosthetic Patient Database (NPPD)*	Recipients of prosthetic, orthotic, and sensory aids from the Veterans Health Administration	√, registry and procedure or diagnosis codes		√			
Veterans Affairs (VA) Decision Support System and Health Economics Resource Center (HERC) average cost databases	Recipients of care from the Veterans Health Administration	√, procedure or diagnosis codes	√	√	√		

*Data source is registry linked to administrative data.
†Data source is survey linked to administrative data.
‡Data on Medicare part D prescription drug services for 2006 will be available starting in 2009. Before 2006, drugs administered parenterally and their administration was covered by Medicare part B, as were Prodrugs, the oral drug equivalent of drugs administered parenterally.

TABLE 6. Individual Level Data Sources Used to Estimate Patient and Caregiver Time

Data Source	Population	Diagnosis Information Available	Time Cost Element				
			Nursing Home Stays in Days	Time in Outpatient Care	Restricted Activity Days	Time in Home Care/ Home Therapy	Hospice Care
American Cancer Society's Quality of Life Survey for Caregivers*	Panel survey of family caregivers of cancer patients identified through registries. Includes information on patient and caregiver characteristics, and average weekly hours spent caregiving. Data collected by mailed survey	√, registry (cancer)					
American Time Use Survey (ATUS)	US civilian noninstitutionalized persons aged 15 and older in households that completed their 8th interview for the Current Population Survey. Data are collected through telephone interviews			√		√	
Cancer of the Prostate Strategic Urologic Research Endeavor (CaPSURE)	Longitudinal study of prostate cancer patients in community practice. Physicians provide clinical assessment of patients during treatment, including method of diagnosis, and results of all procedures and lab tests	√, chart or medical record	√		√	√	√
Medicare Current Beneficiary Survey (MCBS)	Nationally representative sample of aged, disabled, and institutionalized Medicare beneficiaries	√, self-report, chart, and procedure or diagnosis codes		√		√	√
Medicare Health Outcomes Survey (HOS)	National survey of a random sample of Medicare beneficiaries continuously enrolled for 6 mo or longer in managed care health plans. All plans with Medicare Advantage contracts participate	√, self-report			√		
Midlife Development in the United States Survey (MIDUS)	Series of national surveys of adults in midlife. Also surveys of siblings of the general population respondents, and a twin pairs sample	√, self-report			√		
National Ambulatory Medical Care Survey (NAMCS)	Sampled visits to US nonfederal office-based physicians primarily engaged in direct patient care. Data are recorded by physicians and staff	√, chart or medical record		√			
National Caregiver Survey*	National survey of caregivers providing one or more Activities of Daily Living (ADL) or Instrumental ADLs for someone aged 18 or older. Includes weekly hours spent caregiving. Data collected by telephone interview	√, self-report					
National Comorbidity Survey (NCS)	The NCS was originally fielded in 1990–1992, and is a nationally representative mental health survey in the US with diagnostic interviews. Respondents were reinterviewed in 2001–2002	√, self-report			√		
National Health Interview Survey (NHIS) (Core)	Nationally representative sample of US civilian noninstitutionalized population. Data are collected via a personal household interview	√, self-report			√		
NHIS (1992 Cancer control supplement)	Nationally representative sample of US civilian noninstitutionalized adults aged 18 or older. Data are collected via a personal household interview	√, self-report		√			
NHIS (1994–1995 Disability Phase I supplement)	Nationally representative sample of US civilian noninstitutionalized children. Questions about home therapy time only for children. Data are collected via a personal household interview	√, self-report				√	
National Home and Hospice Care Survey (NHHCS)	National sample of home health agencies and hospices and their current and discharged patients. Data are collected by administrators and through personal interviews with staff	√, chart or medical record				√	√

(*Continued*)

TABLE 6. (*Continued*)

Data Source	Population	Diagnosis Information Available	Time Cost Element				
			Nursing Home Stays in Days	Time in Outpatient Care	Restricted Activity Days	Time in Home Care/ Home Therapy	Hospice Care
National Hospital Ambulatory Medical Care Survey (NHAMCS)	National sample of visits to emergency and outpatient departments of nonfederal general and short-stay hospitals. Data are collected by hospital staff	√, chart or medical record		√			
National Mortality Followback Survey (NMFS)	National sample of death certificates for individuals aged 15 yr and over who were residing and died in the United States. Survey is completed by next of kin or another person familiar with the decedent's life history	√, proxy report	√		√		
National Nursing Home Survey (NNHS)	Nationally representative sample of US nursing homes, and their services, staff, and residents. Data are collected through surveys of nursing assistants and personal interviews.	√, chart or medical record	√				
National Survey of Ambulatory Surgery (NSAS)	Ambulatory surgery cases from a nationally representative sample of nonfederal hospital-based and freestanding ambulatory surgery centers	√, chart or medical record		√			

Information on length of hospital stay available from hospital discharge data listed in Table 3 and administrative data with inpatient information listed in Table 4.
*Data collected as the total amount of time spent providing patient care and specific elements not available separately.

national level.[23,26] Data sources at the service level of aggregation included hospital and other discharges, fee or cost schedules for physician services, ambulatory services, and equipment or prescriptions. Government agencies sponsored the majority of the data sources. Most data sources were national or nationally representative. A sizable portion were surveys, followed by administrative data or survey or registry linked to administrative data, fee or cost schedules, hospital discharges, and other types of data. Over 60% of the data sources were cross-sectional. The remaining data sources were longitudinal, including panel data with repeated cross-sections. Many of the data sources provided information about diagnosis with specific diseases, including procedure or diagnosis codes that can be used with algorithms to identify patients with disease, self-reported diagnoses, and registry or chart review identified diagnoses.

The cost elements available in the different data sources included inpatient hospitalization (42.0%), institution or facility (5.7%), physician and other outpatient (45.5%), outpatient pharmacy or laboratory (28.4%), out-of-pocket (22.7%), patient time and other direct nonmedical costs (35.2%), and provider wages (13.6%). About half of the data sources were freely downloadable or available for a nominal fee (ie, $<$\$100), and the cost of acquiring data varied with the scope of the project for the other half.

We classified data sources by level of data aggregation and type of data and listed the available cost elements and source of diagnosis information in Tables 2 to 6. Data sources whose lowest level of data aggregation was at the hospital and provider level are listed in Table 2. Available cost elements include institution or facility, inpatient hospitalization, and wages or payroll. Data sources with the lowest level of data aggregation at the service level include discharges and cost, price, or fee schedules (Table 3). Available cost elements include inpatient hospitalization, outpatient services, and pharmacy and equipment.

Data sources at the individual or patient-level that are surveys and administrative data or administrative data linked to surveys or registries are listed in Table 4 and Table 5, respectively. Detailed cost elements for these patient-level data included inpatient hospitalization, physician or other outpatient services, outpatient pharmacy, out-of-pocket, and other direct nonmedical. Individual level data sources that can be used to estimate patient or caregiver time are listed in Table 6. Time information abstracted included nursing home stays, outpatient services, restricted activity days, home care/ home therapy, and hospice care. Information on length of inpatient hospital stay was available from hospital discharge data listed in Table 3 and administrative data with inpatient information listed in Table 4, and not listed separately in Table 6.

Finally, an alphabetical listing of all data sources with the web address for additional information, and the Table(s) where the data source is described in greater detail is contained in Table 7. Table 7 also includes indicators of whether data were nationally representative and whether longitudinal data were available, and the cost of obtaining the data. Use of several data sources requires collaboration with internal in-

TABLE 7. Alphabetical Listing of Data Sources for Estimating Health Care Costs

Data Source	Website	Appendix Table	Nationally Representative	Longitudinal Data Available	Cost of Data Source: Free Download; or <$100	Cost of Data Source: Depends on Scope of Project; ≥$100
Alcohol and Drug Services Study	oas.samhsa.gov/adss.htm	4	√		√	
Alere databases	www.matria.com	5				√
American Cancer Society's Quality of Life Survey for Caregivers	www.cancer.org/docroot/RES/content/RES_9_1_BRC_Survivorship_Research.asp	6		√, Panel		√*
American Hospital Association (AHA) Annual Survey	www.ahadata.com/ahadata_app/index.jsp	2	√			√
American Hospital Directory	www.ahd.com/	2	√			√
American Time Use Survey (ATUS)	www.bls.gov/tus/	6	√		√	
Area Resource File (ARF)	www.arfsys.com/overview.htm	2	√			√
Blue Cross/Blue Shield	www.bcbs.com/coverage/find/plan/	5		√		√
Cancer of the Prostate Strategic Urologic Research Endeavor (CaPSURE)	urology.ucsf.edu/capsure/overview.htm	6		√		√
Cancer Research Network (CRN)	crn.cancer.gov/	5		√		√*
Centers for Disease Control and Prevention (CDC) Vaccine Price List	www.cdc.gov/vaccines/programs/vfc/cdc-vac-price-list.htm	3	√		√	
Chain Pharmacy Industry Profile	www.nacds.org/wmspage.cfm?parm1=605	3	√			√
Community Health Workers National Workforce Study	bhpr.hrsa.gov/healthworkforce/chw/	2	√		√	
Community Tracking Survey (Household Component)	www.hschange.com/index.cgi?data=12	4	√		√	
Consumer Expenditure Survey (CES)	www.bls.gov/cex/home.htm	4	√		√	
Consumerism in Health Survey	www.commonwealthfund.org/surveys/surveys_show.htm?doc_id=673681	4			√	
Current Employment Statistics (CES)	www.bls.gov/ces/	2	√		√	
Current Population Survey (CPS)	www.bls.gov/cps/	4	√		√	
First DataBank National Drug Data File (NDDF)	www.firstdatabank.com/products/nddf/	3	√			√
Healthcare Cost and Utilization Project (HCUP) Kids' Inpatient Database (KID)	www.hcup-us.ahrq.gov/kidoverview.jsp	3				√
HCUP Nationwide Inpatient Sample (NIS)	www.hcup-us.ahrq.gov/nisoverview.jsp	3	√			√
HCUP State Ambulatory Surgery Databases (SASD)	www.hcup-us.ahrq.gov/sasdoverview.jsp	3				√
HCUP State Emergency Department Databases (SEDD)	www.hcup-us.ahrq.gov/seddoverview.jsp	3				√
HCUP State Inpatient Databases (SID)	www.hcup-us.ahrq.gov/sidoverview.jsp	3				√
Health and Retirement Survey (HRS)-Medicare	hrsonline.isr.umich.edu/rda/medicare.htm	5	√	√		√
Health Maintenance Organization Research Network (HMORN)	www.hmoresearchnetwork.org/about.htm	5		√		√

(*Continued*)

TABLE 7. (*Continued*)

Data Source	Website	Appendix Table	Nationally Representative	Longitudinal Data Available	Cost of Data Source: Free Download; or <$100	Cost of Data Source: Depends on Scope of Project; ≥$100
HIVnet	www.ahrq.gov/data/hivnet.htm	4	√		√	
Human Capital Management Services (HCMS)	www.hcmsgroup.com/hcms/default.aspx	5		√		√
IMS health plan data	www.imshealth.com/portal/site/imshealth	5	√	√		√
Ingenix	www.ingenix.com/	5		√		√
Kaiser Women's Health Study	www.kff.org/womenshealth/whp070705pkg.cfm	4	√		√	
MarketScan Databases	www.medstatmarketscan.com	5		√		√
Medicaid	www.cms.hhs.gov/MedicaidDataSourcesGenInfo/02_MSISData.asp	5		√		√
Medical Expenditure Panel Survey, Household and Provider Components (MEPS)	www.meps.ahrq.gov/mepsweb/	4	√	√, panel	√	
Medical Group Management Association (MGMA), Physician Compensation and Production Survey	www5.mgma.com/ecom/Default.aspx?tabid=138&action=INVProductDetails &args=3823&kc=PHY08WE00; http://www.mgma.com/	2				√
Medicare	www.cms.hhs.gov/FilesForOrderGenInfo/	5	√	√		√
Medicare Ambulance Fee Schedule	www.cms.hhs.gov/ambulancefeeschedule/	3	√		√	
Medicare Ambulatory Payment Classification (APC)	www.cms.hhs.gov/HospitalOutpatientPPS/	3	√		√	
Medicare Clinical Laboratory Fee Schedule	www.cms.hhs.gov/ClinicalLabFeeSched/	3	√		√	
Medicare Cost Reports	www.cms.hhs.gov/CostReports/	2	√		√	
Medicare Current Beneficiary Survey (MCBS)	www.cms.hhs.gov/MCBS/	5, 6	√	√		√
Medicare Diagnosis Related Group (DRG) Fee Schedule	www.cms.hhs.gov/acuteinpatientpps/	3	√		√	
Medicare Durable Medical Equipment, Prosthetics/Orthotics & Supplies Fee Schedules	www.cms.hhs.gov/DMEPOSFeeSched/LSDMEPOSFEE/List.asp	3	√		√	
Medicare Health Outcomes Survey (HOS)	www.hosonline.org/	6	√	√, panel	√	
Medicare Hospital Outpatient Prospective Payment System (OPPS) File	www.cms.hhs.gov/IdentifiableDataFiles/03_HospitalOPPS.asp	3	√			√
Medicare Physician Fee Schedule	www.cms.hhs.gov/PhysicianFeeSched/	3	√		√	
MediQual/Cardinal Health Atlas System	www.mediqual.com/products/atlas.asp	5		√		√
Medispan Drug Database	www.medispan.com/drug-database.aspx	3	√			√
MedMining, a Geisinger Health System business	www.medmining.com	5		√		√

(*Continued*)

TABLE 7. (*Continued*)

Data Source	Website	Appendix Table	Nationally Representative	Longitudinal Data Available	Cost of Data Source: Free Download; or <$100	Cost of Data Source: Depends on Scope of Project; ≥$100
Midlife Development in the United States Survey (MIDUS)	midmac.med.harvard.edu/research.html	6	√	√, panel	√	
National Ambulatory Medical Care Survey (NAMCS)	www.cdc.gov/nchs/about/major/ahcd/ahcd1.htm	6	√		√	
National Association of Psychiatric Health Systems (NAPHS) Annual Survey	www.naphs.org/	2			√	
National Caregiver Survey	www.caregiving.org/data/04finalreport.pdfv	6	√			√
National Comorbidity Survey	www.hcp.med.harvard.edu/ncs/	6	√	√, panel	√	
National Compensation Survey (NCS)	www.bls.gov/NCS/	2	√		√	
National Health and Nutrition Examination Survey (NHANES)–Medicare	www.cdc.gov/nchs/nhanes.htm	5	√	√		√
National Health and Wellness Survey	www.nhwsurvey.com	4	√			√
National Health Expenditure Accounts (NHEA)	www.cms.hhs.gov/NationalHealthExpendData/Downloads/tables_.pdf	†	√		√	
National Health Interview Survey (NHIS) (Core)	www.cdc.gov/nchs/nhis.htm	4, 6	√		√	
NHIS, 1992 Cancer control supplement	www.cdc.gov/nchs/nhis.htm	6	√		√	
NHIS, 1994–1995 Disability Phase I supplement	www.cdc.gov/nchs/nhis.htm	6	√		√	
National Health Interview Survey (NHIS)–Medicare	www.cdc.gov/nchs/nhis.htm	5	√	√		√
National Home and Hospice Care Survey (NHHCS)	www.cdc.gov/nchs/nhhcs.htm	4, 6	√		√	
National Hospital Ambulatory Medical Care Survey (NHAMCS)	www.cdc.gov/nchs/about/major/ahcd/ahcd1.htm	6	√		√	
National Long Term Care Survey (NLTCS)	www.nltcs.aas.duke.edu/index.htm	4	√	√	√	
National Long Term Care Survey (NLTCS)–Medicare	www.nltcs.aas.duke.edu/data.htm	5	√	√		√
National Mortality Followback Survey (NMFS)	www.cdc.gov/nchs/about/major/nmfs/nmfs.htm	4, 6	√		√	
National Nursing Home Survey (NNHS)	www.cdc.gov/nchs/nnhs.htm	4, 6	√		√	
National Sample Survey of Registered Nurses (NSSRN)	datawarehouse.hrsa.gov/NSSRN.htm	2	√		√	
National Survey of Ambulatory Surgery (NSAS)	www.cdc.gov/nchs/about/major/hdasd/nhds.htm	4, 6	√		√	
National Survey of America's Families (NSAF)	www.rwjf.org/pr/product.jsp?id=29617	4	√		√	

(*Continued*)

TABLE 7. (*Continued*)

Data Source	Website	Appendix Table	Nationally Representative	Longitudinal Data Available	Cost of Data Source: Free Download; or <$100	Cost of Data Source: Depends on Scope of Project; ≥$100
New Beneficiary Data System-Medicare (NBDS)–Medicare	www.ssa.gov/policy/docs/microdata/nbds/index.html	5	√	√		√
Occupational Employment Statistics (OES) Survey	www.bls.gov/oes/	2	√		√	
Organization for Economic Cooperation and Development (OECD) health data	www.oecd.org/statisticsdata/0,3381, en_2649_34631_1_119656_1_1_1,00.html	†	√		√	
Panel Study of Income Dynamics (PSID)	psidonline.isr.umich.edu/	4	√	√, panel	√	
PharMetrics (Integrated Medical and Pharmaceutical Database)	www.pharmetrics.com	5		√		√
Physicians' Desk Reference-Red Book	www.micromedex.com/products/redbook/	3	√			√
Premier Perspective Database	www.premierinc.com/prs/	5		√		√
Quarterly Census of Employment and Wages (QCEW)	www.bls.gov/cew/	2	√		√	
State Medicaid Prescription Reimbursement Information	www.cms.hhs.gov/Reimbursement/20_StateMedicaidRxReimb.asp	3			√	
Surveillance, Epidemiology and End-Results (SEER)-Medicare	healthservices.cancer.gov/seermedicare/	5		√		√
Survey of Income and Program Participation (SIPP)	www.census.gov/sipp/	4	√	√, panel		√
The Second Longitudinal Study of Aging (LSOA II)-Medicare	www.cdc.gov/nchs/about/otheract/aging/lsoa2.htm	5	√	√		√
United Healthcare	www.uhc.com/	5		√		√
United States Renal Data System (USRDS)	www.usrds.org/	5	√	√		√
Veterans Affairs (VA) Decision Support System and HERC average cost databases	www.herc.research.va.gov	5	√	√	√*	
Veterans Affairs (VA) National Prosthetic Patient Database (NPPD)	www.virec.research.va.gov	5	√		√*	
WisdomKing.com	www.wisdomking.com/	3	√		√	

*Use of data requires collaboration with internal investigators.
†Data available only at the national level and not abstracted separately.

vestigators; these data sources are indicated with a footnote. Data sources aggregated at the national level were not abstracted or reported separately, although they are listed in Table 7.

SUMMARY

In this inventory, we identified more than 80 data sources in the United States that can be used to estimate health care costs, and abstracted key characteristics, including sponsor, lowest level of data aggregation, population included, length of observation, source of diagnosis information, and available cost elements. The data sources we identified vary in these dimensions as well as in their accessibility. Some are publicly available and freely downloadable directly from sponsors' websites, others must be purchased, and still others are restricted to the use of researchers or collaborators within sponsors' institutions.

The inventory is as comprehensive as we could make it, but some sources were unavoidably excluded. Additionally, work is ongoing to develop linkages between registries and surveys with administrative data, including linkage among multiple data sources or multiple payors. Recently, investigators were able to link the Michigan cancer registry data with both Medicare and Medicaid.[27] Data linkage efforts with Medicare, Medicaid, and additional data sources, including private payors, are ongoing in other states.

Ultimately, investigators must weigh the strengths and weaknesses of different data sources for their specific research questions. Considerations include the representativeness of the data source to the population of interest, the appropriate level of aggregation, the need for information from single or multiple payors (eg, Medicare, Medicaid, private), types of services or resources measured, period of observation (longitudinal versus cross-sectional), and need for accurate identification of patients with specific conditions (eg, cancer). As illustrated in 2 articles in this supplement, accurate identification of patients for either incidence or prevalence cost estimates is critical in cancer[7,8]; the method of patient identification may be less critical for other diseases. In the case of simulation models, which may integrate cost estimates from multiple sources, similarity of patient populations and types of resources measured across sources may be a key consideration. Other issues, such as periodicity and most recent year of cost data may also be important for studies of trends in health care costs or in studies tracking the dissemination of new therapies. Finally, feasibility, ease, and cost of accessing the data may also be important considerations for selecting the most appropriate data source for estimating health care costs for the specific research question.

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