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Data Resources for Conducting Health Services and Policy Research

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Keywords

data, public health surveillance, household survey data, health services research

Abstract

Rich federal data resources provide essential data inputs for monitoring the health and health care of the US population and are essential for conducting health services policy research. The six household surveys we document in this article cover a broad array of health topics, including health insurance coverage (American Community Survey, Current Population Survey), health conditions and behaviors (National Health Interview Survey, Behavioral Risk Factor Surveillance System), health care utilization and spending (Medical Expenditure Panel Survey), and longitudinal data on public program participation (SIPP). New federal activities are linking federal surveys with administrative data to reduce duplication and response burden. In the private sector, vendors are aggregating data from medical records and claims to enhance our understanding of treatment, quality, and outcomes of medical care. Federal agencies must continue to innovate to meet the continuous challenges of scarce resources, pressures for more granular data, and new multimode data collection methodologies.

INTRODUCTION

Health policy is increasingly complex; major efforts to reform the US health care system are met with partisan divide over core values about the role of government involvement in health insurance coverage. The policies designed and promoted on both sides of the political aisle depend on what we know about current levels of private and public health insurance coverage, the health care needs of the population, and the role of government in financing health care. Our national data resources serve as inputs for policy analysis and projection models that inform this intense policy debate.

In this article, we provide an overview of key federal household surveys that are used in health services policy research. We present information on elements of each resource, describing their strengths and limitations, with the anticipation that this synthesis will be used as a type of user guide. We include a discussion of innovations in data collection and provide an overview of data linkage projects and relatively new efforts to monitor cost and utilization through the aggregation of patient claims data. We conclude with observations of the future of US household surveys.

We focus our review on data resources that address a broad range of topics and questions and include the general population in their samples. We exclude surveys targeted to a specific topic or target population. We include surveys that are ongoing and currently funded, that follow a regular schedule for data collection, and that provide data access through a public-release process. We include federal administrative data only when linked to national household surveys.

The timing of this review is critical. New advances in data collection and data technology are pushing the field of survey research to think creatively and to design surveys that are useful and efficient and that minimize response burden. The future of the federal surveys and innovations in data collection and linkages will be fundamental to the ability of health services research to inform health policy.

KEY FEDERAL GENERAL POPULATION HEALTH SURVEYS

Health services researchers rely on a range of consistent sources of data available to monitor the impact of social, economic, and health-related policies. **Table 1** provides an overview of the health-related content included in each survey covered in this review. The amount of health-related content varies depending on the main purpose of each survey. The NHIS, BRFSS, and MEPS-HC provide the richest sources of health-related content. However, the NHIS and MEPS-HC have more limited sample sizes, which constrain state-level analysis (see **Table 2**).

American Community Survey

The American Community Survey (ACS) (<https://census.gov/programs-surveys/acs/>) is a general household survey that was designed as a replacement for the long form of the Decennial Census. The ACS provides annual estimates on demographic, socioeconomic, and housing information. The ACS is a continuous mixed-mode survey with mail and Internet (added in 2013) collection; phone and in-person methods are used for nonresponse follow-up. The ACS is a mandatory survey, although there are efforts to make the survey voluntary (<https://thecensusproject.org/>). This change would likely have a negative impact on response rates and increase survey costs (69, 79).

The greatest strength of the ACS is its large sample size and ability to produce estimates for US states and substate geographies, such as congressional districts, counties, and zip-code tabulation areas. The ACS samples ~3.5 million addresses annually (80). The key limitation for health services research is that the ACS does not have in-depth health-related content. Every question on the

ACS requires federal justification (76), which keeps the ACS from responding quickly to changes in policies. Proposed question changes must be approved by the Office of Management and Budget and the Interagency Council for Statistical Policy and go through a content test before implementation (<https://www.census.gov/programs-surveys/acs/methodology/content-test.html>).

Table 1 Health-related content by federal survey^a

Agency	Census Bureau			CDC—states	CDC—NCHS	AHRQ
	ACS	CPS	SIPP-EHC	BRFSS ^b	NHIS	MEPS-HC
	2015	2016	2014 panel	2015	2015	2014
Health insurance coverage						
Uninsured rate	✓	✓	✓	✓	✓	✓
Coverage type	✓	✓	✓		✓	✓
Coverage obtained through exchange		✓	✓		✓	✓
Access to care						
Usual source of care				✓	✓	✓
Informed that provider accepts insurance					✓	
No trouble finding a doctor					✓	
Affordability of health care						
Delayed medical care due to cost					✓	✓
Unmet need due to cost				✓	✓	✓
Changes made to medical drugs due to cost					✓	✓
Trouble paying medical bills					✓	✓
Out-of-pocket expenditures		✓	✓		✓	✓
Health care utilization						
Provider visit in past year			✓	✓	✓	✓
Mental health services					✓	✓
Emergency department visit in past year					✓	✓
Health care quality						
Adult cancer screenings (pap smears, colorectal cancer, mammograms)					✓	✓
Flu shot				✓	✓	✓
Smoking cessation counseling					✓	✓
Health behaviors						
BMI/obesity				✓	✓	✓
Binge drinking				✓	✓	
Smoking				✓	✓	✓
Health outcomes						
Self-reported health status		✓	✓	✓	✓	✓
Activities limited due to mental or physical health difficulty	✓	✓	✓	✓	✓	✓
Chronic disease				✓	✓	✓
Physical environment						
Neighborhood connectedness					✓	
Physical activity				✓	✓	

(Continued)

Table 1 (Continued)

Agency	Census Bureau			CDC–states	CDC–NCHS	AHRQ
	ACS	CPS	SIPP-EHC	BRFSS ^b	NHIS	MEPS-HC
	2015	2016	2014 panel	2015	2015	2014
Geography						
State identifiers available	✓	✓	✓	✓	Only in RDC	Only in RDC
Substate identifiers available	✓	✓		✓		

Abbreviations: ACS, American Community Survey; AHRQ, Agency for Healthcare Research and Quality; BMI, body mass index; BRFSS, Behavioral Risk Factor Surveillance System; CDC, Centers for Disease Control and Prevention; CPS, Current Population Survey; MEPS-HC, Medical Expenditure Panel Survey–Household Component; NCHS, National Center for Health Statistics; NHIS, National Health Interview Survey; RDC, Research Data Center; SIPP-EHC, Survey of Income and Program Participation.

^aSurvey content is based on the questionnaire for the most current year of available data. All the surveys include demographic and economic variables such as age, race/ethnicity, educational attainment, marital status, work status, and income.

^bThe BRFSS includes content in the core questionnaire; US states also have the option to add additional questions through optional modules.

The ACS did not make any updates to its questionnaire to accommodate health reform, unlike the other federal surveys discussed in this article. Questions on exchange participation and subsidies are currently being evaluated on the 2016 Content Test (70); however, with the current political debates involving health reform, these questions might be outdated by the time they are ready for implementation.

Table 2 United States and state sample sizes by federal survey^a

State	ACS	CPS	SIPP-EHC	BRFSS	MEPS-HC
	2015	2016	2014 panel, wave 1	2015	2014
US total	3,147,005	185,487	72,919	434,382	34,875
Alabama	47,476	3,522	1,784	7,950	437
Alaska	6,619	2,361	133	3,657	NA
Arizona	67,014	3,358	2,299	7,946	540
Arkansas	29,605	3,404	2,370	5,256	252 ^b
California	374,943	18,254	6,399	12,601	6,089
Colorado	53,570	2,226	960	13,537	410
Connecticut	35,787	1,848	525	11,899	324
Delaware	9,017	1,890	159	4,070	NA
District of Columbia	6,610	2,974	122	3,994	NA
Florida	194,548	8,230	2,987	9,739	2,017
Georgia	97,854	4,175	2,402	4,678	1,155
Hawaii	14,124	3,111	234	7,163	343 ^b
Idaho	15,725	2,898	311	5,802	NA
Illinois	126,642	5,441	3,728	5,289	1,115
Indiana	66,045	3,070	2,572	6,067	578
Iowa	31,900	1,945	556	6,227	272
Kansas	28,774	2,201	495	23,236	350
Kentucky	44,749	2,120	2,427	8,806	528

(Continued)

Table 2 (Continued)

State	ACS	CPS	SIPP-EHC	BRFSS	MEPS-HC
	2015	2016	2014 panel, wave 1	2015	2014
Louisiana	43,892	4,341	2,472	4,716	402
Maine	13,059	1,323	228	9,063	NA
Maryland	59,332	2,349	974	12,598	685
Massachusetts	68,785	3,517	1,000	9,294	651
Michigan	98,008	3,807	2,586	8,935	931
Minnesota	54,811	2,363	1,030	16,761	454
Mississippi	29,600	3,586	1,878	6,035	366
Missouri	61,586	2,436	1,108	7,307	553
Montana	9,841	3,393	161	6,051	NA
Nebraska	19,089	2,346	254	17,561	NA
Nevada	26,988	2,398	342	2,926	NA
New Hampshire	13,378	2,197	152	7,022	NA
New Jersey	87,815	3,872	1,234	11,465	915
New Mexico	19,072	4,053	2,185	6,734	NA
New York	195,742	7,433	2,567	12,357	1,731
North Carolina	98,184	4,293	2,570	6,698	862
North Dakota	7,869	2,339	128	4,972	NA
Ohio	118,123	4,639	2,788	11,929	884
Oklahoma	37,251	2,913	736	6,943	288 ^b
Oregon	39,992	2,639	763	5,359	411
Pennsylvania	128,145	4,902	3,275	5,740	1,166
Rhode Island	10,563	1,445	174	6,206	NA
South Carolina	48,023	2,864	2,342	11,607	369
South Dakota	8,742	1,875	122	7,221	NA
Tennessee	65,549	3,259	2,411	5,979	600
Texas	259,224	11,735	4,676	14,697	3,332
Utah	29,290	3,080	533	11,401	425 ^b
Vermont	6,326	2,104	92	6,489	NA
Virginia	83,472	3,413	1,246	8,646	889
Washington	71,804	3,195	1,338	16,116	832
West Virginia	18,051	3,517	343	5,957	NA
Wisconsin	58,578	2,361	1,067	6,188	583
Wyoming	5,819	2,472	61	5,492	NA

Abbreviations: ACS, American Community Survey; AHRQ: Agency for Healthcare Research and Quality; BRFSS, Behavioral Risk Factor Surveillance System; CPS, Current Population Survey; MEPS-HC, Medical Expenditure Panel Survey–Household Component; NA, states do not have sufficient sample size to calculate direct estimates; NCHS, National Center for Health Statistics; NHIS, National Health Interview Survey; SIPP-EHC, Survey of Income and Program Participation.

^aSample sizes are from the most current year of available public use data. MEPS-HC state-level data are a special tabulation provided by the AHRQ. The NCHS does not publish or provide state sample sizes for the NHIS because they are considered restricted data. The US total NHIS sample size for 2015 is 103,789.

^bStates do not have enough primary sampling units to calculate direct variance estimates; a generalized variance function can be used.

Current Population Survey

The Current Population Survey (CPS) (<https://www.census.gov/programs-surveys/cps.html>) provides monthly data regarding labor force participation and unemployment for the civilian noninstitutionalized population. It is conducted by the US Census Bureau on behalf of the Bureau of Labor Statistics. The Annual Social and Economic Supplement collects data by phone and in person, on income and health insurance coverage, from February to April of each year. The CPS has additional supplements fielded throughout the year on a variety of topics (81). The CPS samples ~100,000 addresses annually and provides estimates for all US states (77).

After several years of research to improve the measurement of uninsurance (65, 83), the Census Bureau revised the CPS's questions on health insurance coverage and income in 2014. The revised survey also added new questions on health insurance exchange participation, point-in-time coverage and employer offers of coverage (84). Information on monthly insurance coverage data was also added and is currently being assessed for quality and disclosure concerns (82).

The CPS has not historically been used for longitudinal analysis owing to the complexity of the files, but this analysis is supported by the survey design. Work by the Minnesota Population Center (MPC) has linked CPS data over time to make longitudinal analysis easier (67). These linked data are provided through the Integrated Public Use Microdata Series (<https://cps.ipums.org/cps>) and offer new opportunities to leverage CPS content.

Survey of Income and Program Participation

The Survey of Income and Program Participation (SIPP-EHC) (<https://www.census.gov/sipp/>) collects longitudinal data on income and public program participation (e.g., Medicaid and Food Stamps) for the civilian noninstitutionalized population using an event history calendar. The SIPP was reengineered for the 2014 panel to “reduce survey costs and respondent burden” (66; 74, p. 1), eliminating the use of topical modules (78). Households are interviewed in person and by phone once a year for four years. The 2014 SIPP-EHC panel began with a sample of ~53,000 households (78).

The SIPP-EHC has sample sizes designed to be representative for 20 US states, but identifiers for all states are available on the public use files. The SIPP-EHC is designed specifically for longitudinal analysis, which is ideal for studying changes over time; however, it has the longest lag for data release of any of the surveys discussed in this article. The first wave from the 2014 panel (regarding 2013 coverage) was not released until early 2017.

Behavioral Risk Factor Surveillance System

The Behavioral Risk Factor Surveillance System (BRFSS) (<https://www.cdc.gov/brfss/>) collects data regarding behavioral health and related risk factors for the adult civilian noninstitutionalized population, is sponsored by the US Centers for Disease Control and Prevention (CDC), and is administered at the state level. In 2011, the BRFSS updated its telephone-based sampling design to include cell phones (8). All US states and the District of Columbia are required to use the survey's core standardized questionnaire, which can be either fixed or rotated on a biannual basis. States have the option to include additional modules or state-specific questions.

One strength of the BRFSS is its flexibility for US states to add their own content and be agile in responding to changing policies. The flexibility of the BRFSS also creates challenges when working with the data. Comparisons can be difficult if content is asked of only a few states or removed from the core questionnaire.

National Health Interview Survey

The National Health Interview Survey (NHIS) (61) collects data on the health status, health care access and utilization, and health behaviors of the civilian noninstitutionalized population and is sponsored by the CDC's National Center for Health Statistics (NCHS). The in-person survey is conducted continuously throughout the year with ~35,000 households sampled annually (60).

The 2014 and 2015 health insurance coverage estimates were published for all US states and the District of Columbia. Owing to funding constraints, the sample size was reduced in 2016 and insurance coverage estimates for all states are no longer available (9, 46). Researchers conducting analyses requiring state identifiers must go through the NCHS or Census Bureau's Research Data Center (RDC) network.

NCHS has proposed redesigning the NHIS questionnaire in 2018 to reduce response burden and "to establish a long-term structure of ongoing and periodic topics" (59). The family-level questions will be discontinued; much of the content will be incorporated into the sample adult and sample child questions. With most questions asked of only the sample adult and sample child, the redesigned survey will reduce the sample size available for many questions.

Medical Expenditure Panel Survey–Household Component

The Medical Expenditure Panel Survey–Household Component (MEPS-HC) (<https://meps.ahrq.gov/mepsweb/>) collects data on health, health care access, and expenditures and is sponsored by the Agency for Healthcare Research and Quality (AHRQ). The MEPS-HC is a longitudinal survey with participants interviewed in person five times over a two-year period. Participants are selected from households included in the previous year of the NHIS. The sample includes ~13,500 families (3).

Information is also collected from each respondent's health care provider and supplements the household information. The MEPS-HC provides a breadth of health-related information but is not state representative. Only select estimates are released for the larger US states with sufficient sample size. Researchers conducting analyses requiring state identifiers must go through the AHRQ Data Center or the Census/NCHS RDC network.

Harmonization Efforts: NHIS and MEPS-HC

The MPC has made significant efforts to harmonize federal health data that crosses years of data collection. The Integrated Health Interview Series (IHIS), funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development, provides easily accessible integrated microdata for 5.5 million persons surveyed over 50 years, with more than 14,000 variables describing population health. The MPC is currently working on expanding the IHIS by including the MEPS-HC, the most complete source of information on population health care use and expenditures.

Linking NHIS and MEPS-HC

The MEPS household sample is drawn from the pool of respondents to the previous year's NHIS, allowing each MEPS-HC annual release to be linked to the previous year's NHIS annual release beginning with the 1995 NHIS and the 1996 MEPS (43). These linked data files are currently available only through the AHRQ Data Center or the NCHS/CDC RDC network (2).

The NHIS-MEPS linkage allows researchers to access a variety of sociodemographic, health status, and household characteristics included in the NHIS but not the MEPS. For example,

researchers have used these combined data to analyze the medical expenditures of immigrants in the United States (44, 73; <https://cps.ipums.org/cps>); the time and financial burden of caregiving to children with chronic conditions (86); and the effects of Medicaid eligibility on mental health services and out-of-pocket spending on mental health services (25).

LINKING ADMINISTRATIVE RECORDS AND SURVEY DATA

Federal survey data may be linked with administrative data to better understand the health impact of policies but also to reduce respondent burden, improve accuracy, and reduce cost. We highlight data linkages that are currently maintained and updated for general use by extramural researchers. Some of these data are provided as public use files, whereas others can be accessed only as part of the Census Bureau/NCHS RDC network.

NHIS and Death Records Longitudinal Mortality Files

The NHIS for 1985–2009 is linked to longitudinal mortality data from the National Death Index through December 31, 2011 (55) and was last updated in 2013 (79). A limited set of data are available through public use files with more data available as restricted files through the Census Bureau/NCHS RDC network (11). Restricted use files include detailed mortality information for all survey participants (including children) and information on age and cause of death (79). Published studies have used the linked data to evaluate the association between mortality and various health behaviors, conditions, and treatments and to compare mortality rates of different groups adjusted for covariates (12).

NHIS and Centers for Medicare and Medicaid Services

The 1994–2013 NHISs are linked to 1999–2013 Medicare enrollment and claims records collected by the Centers for Medicare and Medicaid Services (53). In each of the last 10 available NHIS samples, approximately 3,000–10,000 NHIS respondents are linked to Medicare administrative data (13–18% of linkage-eligible respondents) (50). Research files are available through the Census Bureau/NCHS RDC network (62).

Researchers have used these data to study hospitalization, readmission, and death among Medicare enrollees (27); to compare rates of self-reported diabetes in the NHIS with rates of diabetes identified in Medicare claims data (13); to study the relationship between moral hazard and the invasiveness of surgical procedures (42); and to assess NHIS measurement error of Medicare coverage (24).

NHIS and Social Security and Benefit History Data

The 1994–2005 NHISs are linked to the Old Age Survivors and Disability Insurance and Supplemental Security Income (SSI) records from the Social Security Administration (SSA) for respondents who agreed to provide their social security numbers along with their name and date of birth (26, 56). Available data include benefits received from and payments to the SSA, eligibility for SSI disability benefits, and the SSA's determination of disability status for individuals receiving or applying for disability benefits. In each of the last 10 available NHIS samples, 30,000–46,000 NHIS respondents are linked to SSA administrative data (44–62% of any given NHIS sample) (26). SSA-linked data are confidential and are available only through the Census Bureau/NCHS RDC network (58).

NHIS and Department of Housing and Urban Development

The 1990–2012 NHIS are linked to Housing and Urban Development (HUD) administrative data from 1999 through 2014 (40, 54). The administrative data include information on participation in public housing, type and timing of housing assistance received, and housing structure (57). Approximately 1,300–2,600 respondents were linked in each of the last 10 NHIS survey years (~8–10% of linkage-eligible respondents) (51). HUD-linked data are confidential and are available only through the Census Bureau/NCHS RDC network (54).

NEW AGGREGATE HEALTH CARE CLAIMS DATA

The private sector has responded to the need for aggregate claims data to provide information on the trends in use and cost of health care services. Several firms serve as data aggregators that harmonize claims data across multiple payers, creating large-scale big data for the purposes of data analytics and research. These data vendors vary by the number and type of participating health plans and by the accessibility of the data for health services research. **Table 3** reviews four of the key data vendors and includes information on sample coverage, sample size, geographic coverage, and key variables.

Table 3 Health care claims databases

	FAIR Health	MarketScan	Health Care Cost Institute Database	Optum Labs Data Warehouse
Organization that owns the data	FAIR Health Inc. (private nonprofit)	Truven Health Analytics (private for-profit)	Health Care Cost Institute (private nonprofit)	Optum (subsidiary of UnitedHealth Group; public, for-profit)
Data contributors	About 60 national and regional private insurance carriers and third-party administrators (19, 63)	150 employers (28), 21 commercial health plans (28), Medicare and Medicaid (16)	Aetna, Humana, Kaiser Permanente, and UnitedHealthcare (33)	Affiliated and nonaffiliated commercial health plans, provider EMR/EHR systems (64)
Sample size	150 million covered lives, data gathered from about 25 billion claims (19). Represents 75% of privately insured population (19)	230 million unique patients (since 1995); most recent year includes 50 million covered lives (28)	Claims related to 50 million unique people including individual, group, and Medicare Advantage members (31) (25.3% of nonelderly population with ESI)	150 million unique lives: 19% of US population in commercial health plans, 19% of those in Medicare Advantage plans, 24% of those in Medicare PDP plans, and 7% of US population with any health care utilization (64)
Geographic coverage	Covers every locality in United States (19)	Wide geographic range but disproportionately covers South (5). 10–12 unidentified US states for Medicaid sample (28)	Unknown	Relatively geographically representative, concentrated in the South and Midwest (64)

(Continued)

Table 3 (Continued)

	FAIR Health	MarketScan	Health Care Cost Institute Database	Optum Labs Data Warehouse
Variables of interest				
Geographic level	Geozip (first three numbers of ZIP code), can be aggregated to state/MSA level	Geozip (first three numbers of ZIP code), can be aggregated to state/MSA level (5)	ZIP code of populations greater than 1,350 (34). Core based statistical area (only metro areas with 50,000+ populations included)	Not clear—at least available by Census region
Race/ethnicity	Unknown	Only for Medicaid (45)	No	Yes
Age	Yes (date of birth)	Yes (date of birth) (28)	Yes (date of birth) (34)	Yes
Other demographics	Receives patient demographics, such as gender, and provider information, such as specialty, location, and, in many cases, provider NPI	Gender, aid category for Medicaid populations (blind/disabled, Medicare eligible), employment status, relationship of patient to beneficiary, urban/rural status (48)	Gender, relationship to policy holder	Gender, sociodemographic characteristics (85), including race, income, education, assets, health risk assessment, mortality available via linked secondary data sources (34)
Inpatient	✓	✓	✓	✓
Outpatient	✓	✓	✓	✓
Pharmacy	✓	✓	✓	✓
Lab	✓	✓	✓ (29)	✓
Behavioral	✓	✓ (17)	✓ (35)	✓
Dental	✓	✓		
Type of claim: fee charged versus paid claim	All claims contain the fee billed by provider. Over 65 % of claims report “allowed amount” (63)	Claims represent the allowed amount paid by the plan (5)	Claims represent the allowed amount paid by the plan (34)	Claims represent actual paid amounts (6)
Run-out period	For billed charges, benchmarks are updated twice yearly and, for allowed amounts, annually. Claims have a three-month run-out (19)	Analysts can choose between “early view data” with no minimum run-out, “standard updates” with 3-month minimum run-out, and “annual file” with at least 6 months run-out (28)	Annual claims submitted at end of calendar year (31). Claims have a 5–6 month run-out period depending on payer (30)	Unknown

Abbreviations: EMR/EHR, electronic medical record/electronic health record; ESI, employer-sponsored insurance; MSA, metropolitan statistical area; NPI, National Provider Identifier; PDP, prescription drug plan.

FAIR Health

FAIR Health was established in 2009 as part of a legal settlement concerning New York State health insurance industry reimbursement practices (<http://www.fairhealth.org/About-FH>). FAIR Health receives data from 60 contributors, including insurers and third-party administrators, and represents 150 million covered lives, approximately 75% of the privately insured

population and 23.4% of national payments by privately insured patients. Costs for accessing the data are made on a case-by-case basis.

Researchers have used FAIR Health data to study the effects of medical malpractice damage caps on provider reimbursement (22), market power and provider consolidation (39), the effects of occupational licensing on health care prices (38), the effects of health coverage mandates on provider reimbursement (21), and the opioid crisis among the privately insured, among other topics (18).

MarketScan Research Databases

MarketScan Research Databases are a product of Truven Health Analytics, a subsidiary of IBM (7), which includes data from 150 employers, 21 commercial health plans, and Medicare and Medicaid (14). The databases cover 230 million unique patients since 1995, and the most recent year includes 50 million covered lives (28). Researchers can analyze MarketScan data with Truven's proprietary analytic tools or on their own through licensing agreements.

Researchers have used MarketScan data to investigate the relationship between physician practice competition and physician service prices (5), the effects of managed care on angioplasty procedure prices (14), the impact of cost sharing on treatment adherence and outcomes among patients with diabetes (23), the relationship between incentive-based drug formularies and drug selection and spending on hypertension (37), the impact of hospital market consolidation on health care prices (47), and the causes of the 2009–2011 slowdown in health care spending (68).

Health Care Cost Institute Database

Health Care Cost Institute (HCCI) is a private nonprofit established in 2011 to collect and disseminate health care cost and utilization data for Americans with private health insurance (<http://www.healthcostinstitute.org/about-hcci/>). Most of its funding comes from its four data contributors—Aetna, Humana, Kaiser Permanente, and UnitedHealthcare (29)—and its data cover 50 million individuals (30). The data cover 25% of the nonelderly population with employer-sponsored coverage (30). Researchers can access HCCI data through its Data Enclave, a secure, virtual environment hosted by NORC at the University of Chicago that allows HCCI to maintain data security requirements (32).

Researchers have used HCCI data to examine the trends driving the growth in health spending among those with employer-sponsored coverage (36), the relationship between structural change in the health sector and health spending (15), the relationship between regional hospital prices and health spending (10), differences in reimbursement rates between Medicare Advantage and Medicare fee-for-service (4), and out-of-pocket spending on inpatient medical services among the nonelderly (1).

Optum Labs Data Warehouse

Optum Labs was founded as a partnership between Optum (a subsidiary of UnitedHealth Group, a public for-profit health insurer) and the Mayo Clinic in 2013 and includes data from providers' electronic health record systems as well as from claims and enrollment systems of affiliated and nonaffiliated health plans. The data cover 150 million lives: 19% of the population in commercial health plans, 19% of those in Medicare Advantage plans, 24% of those in Medicare Part D only plans, and 7% of the US population with any health care utilization. So far, researchers have not published work using Optum Labs data to investigate questions related to health policy.

CONCLUSIONS

The US federal survey resources are essential for monitoring trends in the nation's health, health insurance coverage and access to needed care, and health care spending. Yet, federal surveys face significant challenges, including resource constraints and pressures to demonstrate surveys' perceived utility in real time (<https://thecensusproject.org/>). For example, some federal surveys are more agile than others in responding to the need for timely data and adding survey content in response to shifts in the policy environment. For example, the NHIS significantly expanded its content in anticipation of ACA implementation, and early-release data from the NCHS are the first indicators on health insurance coverage, released in the first quarter of the year reporting on prior year coverage (71).

Additional challenges stem from trends in survey research that include falling response rates, increases in nonresponse bias, and changing modes of data collection. For example, in 1997 the NHIS achieved a 92% household response (49), which fell to ~70% in 2015 (52). Surveys must be responsive. The ACS has gone a long way to meet respondent preferences by offering mail and online survey options as well as telephone and in-person follow-up for nonresponders. Although response rates are but one measure of quality, to date, studies examining trends in bias between 1995 and 2015 are reassuringly stable (D. Dutwin & T. Buskirk, unpublished manuscript, "Telephone sample surveys: dearly beloved or nearly departed? Trends in survey errors in the age of declining response rates").

Maintaining and assuring privacy are also challenging as Americans signal a growing mistrust of the government regarding privacy and confidentiality concerns (41). Leveraging administrative data is one option to reduce respondent burden, improve accuracy, and reduce costs (72, 75). This approach is appealing particularly for sensitive topics, such as income, that have high rates of missing data, which could be accessed through an administrative data source. Again, this method is not without challenges, given issues of confidentiality and a need for cooperation within agencies and across sectors (43).

Finally, some questions of interest to health services research require detailed data on the use and costs of services—data that stretch the limits of self-report in surveys. This need has motivated the development of new frontiers in the data resource landscape such as aggregated claims data from private sources. Health services researchers have much to discover and document about the strengths and limits of new data resources, while continuing to rely on available federal surveys and linked data resources. Federal agencies will need to continue to innovate to keep pace with the changes in survey methodology and with trends in health and health care during a time of increased demands for data with limited resources.

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