Linking State Health Care Data to Inform Policymaking:

Opportunities and Challenges

The Office of the Assistant Secretary for Planning and Evaluation (ASPE)
at the U.S. Department of Health & Human Services

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The Office of the Assistant Secretary for Planning and Evaluation

The Assistant Secretary for Planning and Evaluation (ASPE) advises the Secretary of the U.S. Department of Health and Human Services (HHS) on policy development in health, disability, human services, data, and science; and provides advice and analysis on economic policy. ASPE leads special initiatives; coordinates the Department's evaluation, research, and demonstration activities; and manages cross-Department planning activities such as strategic planning, legislative planning, and review of regulations. Integral to this role, ASPE conducts research and evaluation studies; develops policy analyses; and estimates the cost and benefits of policy alternatives under consideration by the Department or Congress.

Introduction

In 2021, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) commissioned RAND to prepare a report providing contextual background on state all payer claims databases (APCDs) to help inform the deliberations of the Department of Labor's State All Payer Claims Database Advisory Committee. That report provided information on the status of APCDs across the states, how they have been used, and their strengths and limitations. The below report updates the initial report and provides additional detail on current ACPD data collection and data access procedures, describes additional use cases, and discusses some of the most important challenges associated with operating an APCD or working with APCD data.

This cover memo is a companion piece describing the U.S. Department of Health and Human Service's interest in APCDs; how, if information from APCDs was standardized, harmonized, and linked across states, such a resource could be used to address many issues of major state and national interest; and initial steps the Department is taking towards developing such a resource with the ultimate goal of advancing healthcare transparency and improving care delivery. RAND's report is helping to inform this activity. RAND's report is helping to inform development of this project, which is a first step towards the objective of the President's Fiscal Year 2023 budget request to build a national-level APCD.

The building blocks for health services research, informed policy making, and health care system transparency are composed of data. Ideally, these data track how well individuals are served by our health care system across the country, over time, and across payers. The federal government, state and local policymakers, and researchers need these kinds of data to assess where there are health care challenges to be addressed and to develop evidence-based programs and interventions to improve health equity, access to care, quality, health outcomes, and value in health care. Such data can be used to monitor, research, and address major national concerns such as the alarming decrease in life expectancy that has occurred in the United States over the last several years, the opioid epidemic, the impacts of the coronavirus pandemic and long-COVID, cancer research, and other pressing health care policy issues, in the context of over $4 trillion in U.S. spending on health care.

The data we need often already exist, but they frequently reside in siloed repositories. The data can be difficult, expensive, or cumbersome to access, and the data elements may not be structured in a way that they can be readily linked and compared with data from other repositories. The National Academy of Science and Education (NASEM) issued a May 2022 report, *Data Capacity for Patient-Centered Outcomes Research: Priorities for the Next Decade*, that highlights the need for a more robust data infrastructure that includes data on the cost of care and social drivers of health (among other issues), and that provides data that can be tracked longitudinally and linked across databases.[1] The Office of the Secretary will be using the Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) to help support this goal.

One project being launched with funding from the OS-PCORTF is an effort to build a pilot database with a goal of providing greater transparency into the outcomes, effectiveness, and costs of our health care system, building on a base of health care claims data currently being collected at the state-level. While a growing body of academic and policy research is demonstrating the value of state collected claims data for health care research, such data resources have various limitations, as discussed in greater detail below. One of the most notable limitations is that research findings using these data may be limited in in scope to the state collecting the data. Even if a researcher is able to gain access to data from multiple states, it may not be readily possible to combine data across states to support regional or national research, because the data from different states may not share a common format or critical variables may be defined differently across APCDs.

State APCD Background

As discussed in RAND's report, there is increasing attention at both state and national levels on state APCDs as tools to increase transparency of health care prices, resource use, and quality of care that can contribute to data-informed policy development. APCDs are large databases that include medical claims, pharmacy claims, dental claims, and enrollment and provider files collected from private and public payers by states, usually as part of a State mandate.[2] Today, a total of 25 states have either a mandatory APCD (with statutorily-mandated reporting from covered payers) or a voluntary APCD,[*] and an additional six states are currently developing mandatory APCDs. An important shortcoming of APCDs is that the 2016 Supreme Court Gobeille decision precluded states from requiring reporting to APCDs by self-insured private employers and third-party administrators operating health plans regulated under the Employee Retirement Income Security Act of 1974 (ERISA).[†] These plans cover over 60 percent of those with employer-sponsored insurance and are regulated by the Department of Labor. The Consolidated Appropriations Act, 2021 took one step to address this limitation through its No Surprises Act provisions.[3] The Act required the Department of Labor to establish an Advisory Committee to produce a report with recommendations for a standardized reporting format for ERISA group health plans to voluntarily report to state APCDs and to offer guidance to the states on the use of the standardized reporting format.[‡] To support the Committee, which had several representatives from across the Department of Health and Human Services (HHS), as noted above the Office of the Assistant Secretary for Planning and Evaluation (ASPE) commissioned

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[*] Note that California Washington, and Texas have both voluntary and mandatory efforts, as voluntary efforts were in place prior to mandatory efforts began.

[†] These are plans in which the employer accepts the risk for paying out claims instead of the insurance company itself, which acts only as a third-party administrator to manage claims processing and other administrative responsibilities associated with operating a health plan.

[‡] That report was submitted to Congress in the Fall of 2021. It can be found at: https://www.dol.gov/sites/dolgov/files/ebsa/about-ebsa/about-us/state-all-payer-claims-databases-advisory-committee/final-report-and-recommendations-2021.pdf

RAND to prepare a background report on APCDs that provided information on their current status across the states, how they have been used, and their strengths and limitations.[4]

Case Studies of Research Using State APCD Data

There is broad interest across the Department in being able to utilize data to inform research and policy development. Topics of particular interest within the Department are related to efforts to mitigate the opioid epidemic, improve health system resiliency, advance cancer screening and treatment, evaluate continuity of health insurance coverage across payers, and prevent, manage chronic disease, and examine the impact of COVID-19. In the future, APCD data could also potentially be linked with vaccination data. Many, if not all, of these priorities are shared by state governments, policy institutes, academic researchers, and other policy analysts. Research on state APCDs can be conducted by outside researchers, often supported by federal research grants or research foundations. Research may also be conducted by states or state-contracted researchers in response to state legislative mandates and regard an issue of critical state interest.

Creating a standardized and harmonized national-level APCD would allow for cross-state comparisons on important health policy topics and build upon the statistical power of each individual state APCD to enable regional- and national-level generalizability of research findings, in addition to analysis of rare but important conditions. In this section, we provide several illustrative examples of policy-relevant research using APCD data.

Wasteful Spending in Utah: A 2020 Utah statute, “Identifying potential overuse of non-evidence-based health care,” required the state to contract with a nationally-recognized health waste calculator and use the calculator to analyze data in its APCD to identify potential overuse of non-evidence-based care. The inquiry by Utah’s Department of Health Office of Health Statistics analyzed 48 measures of potentially wasteful services in the state’s 2019 APCD. The study found approximately 5% of total spending to be wasteful or likely to be wasteful ($42 million out of $830 million).* They also analyzed wasteful spending by payer, age group, and patient’s urban/rural status. The top three health waste measures across the state among adults were opiates in acute disabling low back pain, two or more antipsychotic medications, and annual resting EKGs. They used their findings to engage stakeholders in conversations about how best to communicate their findings, better highlight best practices, and align quality measures.[5] Utah has also used its APCD data to provide information about variation in costs for common procedures like colonoscopies,[6] cataract surgery,[7] and hip and knee replacement.[8]

Primary Care Quality in Colorado: In Colorado, the state’s Primary Care Payment Reform Collaborative is a legislatively established committee convened by the Division of Insurance. Since 2019, the Collaborative has been meeting to develop recommendations aimed at increasing

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* Before Medicaid rebates applied for two selected measures: opioids for acute disabling low back pain and two or more antipsychotic medications; the amount after applying the rebates was approximately $38 million

investments in high-quality primary care. The Collaborative uses information derived from the state's APCD to develop its recommendations and help inform state payment policies to better support primary care. This year, the recommendations will be used to assist the Colorado Insurance Commissioner in the development and implementation of affordability standards for health insurance carriers in Colorado and has been used to set primary care spending targets for the state.

Primary Care Spending Targets Across States: The American Academy of Family Practice has identified five states that have used their APCD data to set mandatory minimum thresholds for the percentage of medical spending dedicated to primary care. In addition to Colorado, Delaware and Oregon have legislated primary care spending targets. Rhode Island did so through regulation, while Connecticut set a primary care spending target of 10 percent of all health care expenses by 2025 through Executive Order[9].

Opioid Prescribing in Virginia: APCD data sets can be linked with other data sets to provide deeper insight into the treatment of major conditions. A particularly promising approach is linking state APCD and cancer registry data. Researchers have done this in Virginia to examine opioid prescribing patterns for cancer patients in southwest Virginia, an area with high fatality rates from both cancer and opioid misuse, with findings suggesting potential undertreatment of cancer-related pain.[10]

Cancer Genetic Testing in Massachusetts: A recently published article from Massachusetts used linked APCD and cancer registry data to demonstrate that despite nearly universal health care insurance coverage in that state between 2010 and 2014 there were socioeconomic and racial/ethnic disparities in BRCA1/2 testing[*] in women with cancer.[11]

Marijuana Use in Arkansas: An ambitious example of state data linkage is occurring in Arkansas, in order to gain a comprehensive view of the impact of cannabis on patient medical care. With support from the National Institute of Drug Abuse, researchers at the Arkansas Center for Health Improvement and the University of Arkansas for Medical Sciences are using linked data from the Arkansas APCD, the Arkansas Department of Health medical marijuana patient registry, medical marijuana dispensary purchases, vital records, emergency department records, and Arkansas State Police motor vehicle crashes to analyze this issue. This study, the first of its kind, will also examine the impact of COVID-19 on the Arkansas medical marijuana program.[12]

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[*] BRCA1/2 are the genes most commonly affected in hereditary breast and ovarian cancer. Testing for mutations in these genes can provide information on your potential level of risk of developing cancer.

Looking Forward

While a number of state APCDs were built, in part, using federal funding, they do not receive federal support on an ongoing basis to support their operations.[*] The continually growing number of states operating or developing APCDs illustrates the value states see in these resources. The value of such resources is further evidenced by the growing body of academic and policy research being conducted on state APCD data. While individual state APCDs have proven themselves to be informative resources for analyses of health policy topics at the state level, they do not easily allow for cross-state analyses because they vary in how they report data, as described in greater detail in the below report.

A similar situation once existed for hospital discharge data. Over a number of years, AHRQ was able to work with individual state entities contributing their data to the Healthcare Cost and Utilization Project (HCUP) to establish a common data model across state-level discharge databases. This effort began with a handful of participating states and is now the largest interconnected hospital-based data resource, representing 48 states and the District of Columbia. This resource is regularly used by health policy analysts to address national level research on a wide variety of topics including informing the distribution of ventilators during the early months of COVID as well as assisting federal, state, and local officials when they need to determine how best to deploy medical resources in response to national disasters. Building a national level APCD would go beyond hospital data and could one day allow for a similar level of analytic rigor applied to some of the nation’s most pressing health care challenges.

This is the vision for the President’s FY2023 budget request and initial pilot work with states that will be undertaken by the Department in the coming months to prepare for a potentially more comprehensive initiative.

[*] A grant program that would fund establishing or augmenting state APCDs authorized in the Consolidated Appropriations Act, 2021 is yet to be funded.

[1] National Academies of Sciences, Engineering, and Medicine. (2022). *Building Data Capacity for Patient-Centered Outcomes Research: Priorities for the Next Decade*. Washington, DC: The National Academies Press.

[2] https://www.ahrq.gov/data/apcd/index.html#:~:text=All-payer%20claims%20databases%20%28APCDs%29%20are%20large%20State%20databases,States%2C%20usually%20as%20part%20of%20a%20State%20mandate.

[3] Consolidated Appropriation Act, 2921, Division BB, Title I, https://www.congress.gov/bill/117th-congress/house-bill/2471/text

[4] https://aspe.hhs.gov/reports/history-promise-challenges-state-all-payer-claims-databases-background-memo-state-all-payer-claims

[5] Identifying Potential Overuse of Non-Evidence-Based Health Care in Utah, Utah Department of Health, Office of Health Care Statistics, Center for Health Data and Informatics https://health.utah.gov/wp-content/uploads/UDOH-OHCS-Waste-Calculator-Report-FINAL-10.31.21.pdf

[6] Exploring the Cost of Colonoscopy in Utah, Utah Department of Health, Office of Health Care Statistics, Center for Health Data and Informatics https://stats.health.utah.gov/wp-content/uploads/2021/03/Exploring-the-Cost-of-Colonoscopy-in-Utah-FINAL-3.23.21.pdf

[7] Exploring the Cost of Cataract Surgery in Utah, Utah Department of Health, Office of Health Care Statistics, Center for Health Data and Informatics https://stats.health.utah.gov/wp-content/uploads/2021/03/Exploring-the-Cost-of-Cataract-Surgery-in-Utah-FINAL-3.23.21.pdf.

[8] Galli-Graves L and Scott B. Databyte: A Snapshot of Hip and Knee Replacements and Cost in Utah, December 6, 2021. https://stats.health.utah.gov/latest-news/databyte-a-snapshot-of-hip-and-knee-replacements-and-cost-in-utah/

[9] https://www.aafp.org/dam/AAFP/documents/advocacy/payment/apms/BKG-PrimaryCareSpend.pdf

[10] LeBaron V, Camacho F, Balkrishnan R et al. Opioid Epidemic or Pain Crisis? Using the Virginia All Payer Claims Database to Describe Opioid Medication Prescribing Patterns and Potential Harms for Patients With Cancer, Journal of Oncology Practice, December 1, 2019.

[11] Gershman ST, Hawkins SS, Keating NL. BRCA1/2 testing among young women with breast cancer in Massachusetts, 2010-2013: An observational study using state cancer registry and All-Payer claims data. Cancer Med. 2022 Mar 21.

[12] https://achi.net/news-releases/achi-leads-first-of-its-kind-study-to-analyze-impact-of-medical-marijuana-in-arkansas/

State All Payer Claims Databases

Understanding the Current Landscape and Challenges to Use

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About This Project Report

In this report, RAND researchers provide the U.S. Department of Health and Human Services' (HHS') Office of the Assistant Secretary for Planning and Evaluation (ASPE) with background information on All Payer Claims Databases (APCDs). This report is an update of work previously published for ASPE to support its role with the U.S. Department of Labor's State All Payer Claims Databases Advisory Committee (SAPCDAC). The purpose of this document is to provide a primer on the history of the development and goals of APCDs, discuss the current data collection and data access procedures of APCDs, and discuss some of the most important challenges and limitations associated with operating an APCD or working with APCD data.

This document builds on a project report provided to ASPE by RAND in 2021; some text therefore draws heavily on the previous report. However, this document is also intended to serve a wider variety of audiences than RAND's 2021 report (which was focused more narrowly on informing the SAPCDAC). This report contains additional detail on the objectives of and use cases for APCDs, the current APCD landscape, and implementation challenges that constrain the use of APCDs for some valuable applications. Federal and state policymakers, researchers, and other stakeholders who are interested in understanding the current APCD landscape might find this work useful.

This report updates the June 2, 2021, report titled *The History, Promise and Challenges of State All Payer Claims Databases: Background Memo for the State All Payer Claims Database Advisory Committee to the Department of Labor* (Carman et al., 2021).

Acknowledgments

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Contents

Abbreviations

ACS	American Community Survey
AHRQ	Agency for Healthcare Research and Quality
APCD	All Payer Claims Database
ASPE	Office of the Assistant Secretary for Planning and Evaluation
CDL	Common Data Layout
CIVHC	Center for Improving Value in Health Care
CHAMPVA	Civilian Health and Medical Program of the Department of Veterans Affairs
CMS	Centers for Medicare & Medicaid Services
DOL	U.S. Department of Labor
EDI	Electronic Data Interchange
ERISA	Employee Retirement Income Security Act
ESI	employer-sponsored insurance
FEHBP	Federal Employee Health Benefits Program
HCCI	Health Care Cost Institute
HCUP	Healthcare Cost and Utilization Project
HHS	U.S. Department of Health and Human Services
IHS	Indian Health Service
KFF	Kaiser Family Foundation
NAHDO	National Association of Health Data Organizations
NPI	National Provider Identifier
SAPCDAC	State All Payer Claims Databases Advisory Committee
SSN	Social Security Number
VHA	Veterans Health Administration

1. Introduction

Purpose

In this report, RAND Corporation researchers provide the U.S. Department of Health and Human Services' (HHS') Office of the Assistant Secretary for Planning and Evaluation (ASPE) with background information on All Payer Claims Databases (APCDs). This report is an update of work previously published for ASPE to support its role with the U.S. Department of Labor's (DOL's) State All Payer Claims Databases Advisory Committee (SAPCDAC). The SAPCDAC was convened pursuant to a requirement included in the Consolidated Appropriations Act of 2021 with the goal of developing recommendations for a standardized reporting format that might be used for voluntary reporting by self-funded group health plans to state APCDs (Pub. L. 116-260, 2020). In a series of meetings between May 2021 and July 2021, the SAPCDAC developed a set of 14 recommendations. In addition to providing DOL with guidance on how to choose a standardized reporting format for voluntary reporting by self-funded group health plans, the SAPCDAC suggested some further actions that DOL, HHS, state APCDs, and other parties might consider to "strengthen the path toward actionable data and effective data-driven health care transformation" (DOL, 2021, p. 2).

ASPE asked us to update and expand on our 2021 report and provide a deeper understanding of the APCD landscape. This report has several purposes:

1. to provide a primer on the history of the development and goals of APCDs
2. to summarize an environmental scan describing the current data collection and data access procedures of APCDs
3. to discuss some of the most important challenges and limitations associated with operating an APCD or working with APCD data.

This report is intended to supersede the project report provided to ASPE by RAND in 2021; some text is therefore drawn heavily from the previous report. However, this report is also intended to serve a wider variety of audiences than our 2021 report (which was focused more narrowly on informing the SAPCDAC). This report contains additional detail on the objectives of and use cases for APCDs, the current APCD landscape, and implementation challenges that constrain the use of APCDs for some valuable applications. Federal and state policymakers, researchers, and other stakeholders who are interested in understanding the current APCD landscape might find this work useful.

Background

State APCDs were originally developed to provide a single source for claims and enrollment data across all (or most) sources of insurance coverage within a state. As their name suggests, multiple payers (i.e., health insurers) submit data on claims and enrollment. By including data from public programs (such as Medicare and Medicaid) and from private insurers (including both employer-sponsored insurance [ESI] and other nongroup insurance), APCDs as originally conceived have the potential to allow the study of utilization, spending, prices, and enrollment across payers accounting for the vast majority of health care spending in the states they cover (Freedman, Green and Landon, 2016). APCDs could enable analyses along the entire continuum of care because they capture claims across all settings of care, as well as prescription drug claims and (in many states) dental claims. A significant limitation, discussed in more detail below, is the omission of many ESI plans and nearly all uninsured individuals, which hinders APCDs' ability to achieve their full potential.

States see APCDs as a key tool to promote price transparency, assess geographic variation in spending and health care utilization, track spending, promote public health, assess policy changes, and improve the provision of health care (Costello et al., 2018). Maryland created the first APCD in 1998. Today, 31 states have mandatory or voluntary APCDs in existence or development (APCD Council, undated-a).

State APCDs are not the first effort in the United States to combine records of patient encounters or insurance claims capturing a wide variety of health care payers: Nearly all states operate databases capturing the universe of hospital inpatient admissions, and a majority have similar databases for emergency department visits or ambulatory surgeries (Healthcare Cost and Utilization Project [HCUP], 2021a). Since 1988, HCUP, which is sponsored by the Agency for Healthcare Research and Quality (AHRQ), has brought together and uniformly standardized these state-level databases to enable national, state-level, and cross-state analyses of hospital care (HCUP, 2021b). Hospital discharge databases such as HCUP's differ from APCDs in several important ways, however: (1) Data are reported from hospitals or other facilities rather than by payers; (2) information on costs reflects charges rather than paid amounts; and (3) nonhospital care and retail pharmacy claims are not observed. Another important difference is who is included: In hospital discharge data, only those individuals who receive care from a hospital or other covered facility are observed. Thus, many who never receive care from a hospital are excluded. However, those who receive care and are uninsured or who pay for care themselves are included in hospital discharge databases but not in an APCD.

Private, multipayer claims databases, such as IBM MarketScan or the Health Care Cost Institute's (HCCI's) commercial claims data set, resemble APCDs more closely. Like APCDs, these proprietary efforts collect enrollment and claims data from private-sector insurers (including Medicare Advantage) or self-insured employers and include claims from all settings, along with pharmacy data. However, they often lack complete data from public payers, such as Medicaid and Medicare fee-for-service claims. Furthermore, these data sets are convenience samples and might not be representative of all private insurance plans or the health care system as a whole.[1]

It was originally thought that state APCDs could be more representative than proprietary claims databases because states can mandate the inclusion of public and private payers. However, an important turning point in the development of APCDs was a March 2016 ruling by the U.S. Supreme Court in *Gobeille v. Liberty Mutual Insurance Company*. In *Gobeille*, the court held that self-insured employer plans regulated under the federal Employee Retirement Income Security Act (ERISA) could not be compelled by state governments to submit data to APCDs. Since *Gobeille*, state APCDs that continue to collect data from self-insured ERISA plans must rely on voluntary participation from employers and third-party administrators, which administer health benefits on behalf of self-insured employers. Challenges posed by the *Gobeille* decision are discussed further in Chapter 2.

Approach

The purpose of this updated report is to extend our previous literature review on the state and extent of reporting requirements to APCDs. The material in this report reflects a literature review and an environmental scan. We also conducted a small number of key informant interviews and have drawn on our team's experience and expertise as researchers who have worked with multiple state APCDs.

In spring 2021, we conducted a review of literature published between 2016 and 2021 using key databases that include published literature (such as PubMed, EconLit, and Web of Science), working papers (including those from the Social Science Research Network and National Bureau of Economic Research), and gray literature.[2] We searched for such terms as *APCD*, *all-payer claims data*, *all payer all claims*, and the names of each state APCD currently available. In

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[1] According to IBM, MarketScan databases offer some of the largest convenience samples available in proprietary U.S. databases, with more than 245 million unique patients since 1995. In the most recent full data year, MarketScan databases contained health care data for more than 41.1 million covered individuals. This database is large enough to allow the creation of a nationally representative data sample of Americans with employer-provided health insurance. The sample from multiple sources (for example, employers, states, and health plans) consists of more than 300 contributing employers, 25 contributing health plans, and representation from more than 350 unique carriers. Additional information is available at IBM MarketScan Research Databases, undated.

HCCI focuses on ESI and contains information on more than 50 million covered individuals each year (HCCI, undated). Like for MarketScan, it is possible to consider these data nationally representative of Americans with employer-provided health insurance.

[2] The full list of databases searched was: Academic Search Complete, Business Source Complete, EconLit, National Bureau of Economic Research, Policy File Index, PubMed, Research Papers in Economics, Scopus, Social Sciences Abstracts, Social Science Research Network, and Web of Science.

addition, we included literature from the APCD Council and commentaries and reports written by key stakeholders.[3]

In 2021, we conducted an environmental scan that focused on the APCD Council website, a selection of state APCD websites, and WestLaw. We conducted an interview with the co-chair of the APCD Council and drew on past interviews with APCD stakeholders. We also drew on our experiences and knowledge from past and present work: The authors have previously worked with six different APCDs and are currently working with many more.

In 2022, we updated our environmental scan: We reviewed the websites of *all* state APCDs with submission mandates and two that are in near-final stages of development. There are several states that have APCDs to which submission is voluntary; these were excluded from our environmental scan. We also excluded states whose APCDs were in development but were not near completion. We developed and used a rubric to record key information about the characteristics of the APCDs, including the structure of the data, contents of the data reporting requirements, and information about who submits to the APCDs. We also reviewed the legislation and regulations that created the APCDs. When key information was missing, we spoke with a representative of the APCD where possible. Two states are excluded from our analysis because limited information was available.

Key Findings

- Several goals were widely cited by state legislatures as the reasons for establishing APCDs in a majority of the 19 states we reviewed that have (18 states) or are developing (1 state) mandatory APCDs. Legislation establishing mandatory state APCDs was most likely to cite price transparency and the ability to track utilization, spending, and quality as motivations for the creation of an APCD. Other goals cited by more than half of states with currently operating mandatory APCDs included quality measurement, improving population health, and reducing or controlling the growth of health care costs.
- APCDs have been widely used to improve price transparency by developing online price comparison tools; some states have also used APCD data to measure and improve quality of care, including at least one example of a public-facing dashboard in Virginia describing regional variation in low-value and high-value services provided in the state.
- APCD data have also been instrumental in the passage and implementation of state-based legislation related to surprise billing, lowering and controlling costs, and ensuring network adequacy. Notably, laws in Colorado, Maine, Virginia, and Washington allow the use of APCDs to identify benchmark prices for use in surprise out-of-network billing cases.

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[3] The APCD Council is a learning collaborative convened and coordinated by the Institute for Health Policy and Practice at the University of New Hampshire and the National Association of Health Data Organizations (NAHDO) with the goals of supporting information-sharing across states that have or are developing APCDs and are providing technical assistance to states.

- Today, a total of 25 states have mandatory APCDs (with statutorily mandated reporting from covered payers) or voluntary APCDs (without a reporting mandate),[4] and an additional six states are currently developing mandatory APCDs.
- The Supreme Court's decision in *Gobeille v. Liberty Mutual Insurance Company* has reduced ERISA plan participation by determining that states cannot mandate claims data reporting for such plans, affecting the representativeness of the employer-sponsored insurance sector in such databases. In some states, the share of lives covered by self-insured plans reported to APCDs could be as low as 25 percent. A majority (approximately three in five) of ESI enrollees are in self-insured plans (including non-ERISA plans offered by governments and churches), suggesting that the missing population created by the *Gobeille* ruling is large. Data on the proportion of all ESI enrollees who are in ERISA plans were not readily available from most states, but several states reported the proportion of the self-insured population captured in the APCD. In these states, the share of lives covered by self-insured plans reported to the APCD might be as low as 25 percent.
- States face potential trade-offs between maximizing the value of an APCD and protecting privacy. For example, unique personal identifiers that allow tracking of patients across submitters can enable more-powerful analysis but can also pose potentially greater privacy risks. One possible solution is to have submitters encrypt personal information to create a unique identifier, but this also introduces limitations.
- The most-notable differences across state APCD formats have to do with file structure; submission methods; collection of direct identifiers, such as name and date of birth; and the creation of a longitudinal identifier to allow the tracking of patients over time across insurance types.
- The APCD Council's Common Data Layout (CDL) provides a set of features that are widely shared and acceptable across states. It was developed in response to the *Gobeille* ruling as a potential starting point for standardized voluntary ERISA submissions to APCDs. The APCD Council's goal was to identify a potential common format that could reduce the burden faced by plans that must submit to multiple states, especially ERISA plans. Currently, the CDL has been adopted by only two newer APCDs (Virginia and California). The CDL was recommended by the SAPCDAC for ERISA plans to help improve the comparability of APCDs across states and reduce the burden associated with data submission.
- APCDs must balance the needs of a wide variety of stakeholders—policymakers, providers, payers, employers, consumers, and researchers. Expanding the use cases of APCDs can benefit more groups but might increase the number of data fields or the complexity of data needed; therefore, it might increase costs and burdens on submitters to prepare submissions.
- Viewing stakeholders as partners can improve the value of APCDs. In particular, engaging with users and submitters can help improve data quality.
- Although APCDs have great value to policymakers and researchers, there are challenges and limitations primarily related to missing populations, missing variables, and data

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[4] California, Texas, and Washington have both voluntary and mandatory efforts; voluntary efforts were in place before mandatory efforts began.

quality. It is important for users to understand the limitations of APCD data and to characterize their findings accurately.

- Although APCDs could be a potential resource for understanding racial and ethnic disparities, race and ethnicity are not always collected by all payers. The National Association of Health Data Organizations (NAHDO) examined the completeness of race and ethnicity data for five APCDs in 2017 and found that the proportion of records with usable data was 28 percent for race and 12 percent for ethnicity. In contrast, APCDs have detailed data about location and health status and are thus already a valuable resource for studying urban versus rural disparities or disparities by health status.
- Differences across states in their data structures, submission guidelines, and requirements about who must report can make cross-state comparisons using APCDs challenging—or, in some cases, inappropriate.

Key Findings from the Environmental Scan

We supplement the key findings from our initial work with several new key findings from our broader environmental scan, which we conducted in 2022:

- Although there are many similarities across states in the implementation of APCDs at a broad level, there are differences in the details.
    - For example, most states develop a longitudinal identifier but differ in the information they use to create it and in their documentation of these efforts.
    - All states collect detailed claims information from a wide variety of health care services, but the structure and organization of their files differ.
- In many states, descriptive statistics reflecting the number of unique individuals captured in the APCD and the completeness or representativeness of the APCD's enrollment data were not readily available either through the APCD website or through follow-up queries sent to APCD staff.
    - Many APCDs appear to cover more than half of their state populations: Among nine states that provided data, the median proportion of the state population appearing in the APCD was 77 percent.
    - The extent of coverage varies widely across states: The proportion of the state population appearing in the APCD ranged from 34 percent to 85 percent.
- Linkages between APCDs and such external databases as cancer registries, vaccination registries, and vital records could enable innovative research and address many missing data and missing population problems that affect APCDs. Although many states collect information that could be used for these linkages, we found very little evidence that states have linked their APCDs to many important external databases. However, evidence of these linkages might be particularly hard to find.

2. History of State APCDs

In this chapter, we describe the reasons why states have chosen to develop and maintain APCDs. We characterize the reasons given by states for developing APCDs, drawing on a review of authorizing state legislation and contemporaneous news articles. We then provide a brief overview of the history of APCDs and which states are currently operating or developing them. We then discuss how APCDs have been used to support policymaking, promote public health, and enable research, drawing on a literature review and environmental scan conducted in 2021.

Goals of APCDs

The creation of APCDs has been motivated by a wide variety of goals (McCarthy, 2020), including the following:

- public reporting on utilization, spending, and quality
- facilitating price transparency and consumer price shopping for care
- measuring quality of care
- improving the health of the population
- reducing or controlling the growth of costs
- supporting health system change, such as implementation of accountable care organizations or other alternative payment models
- evaluating state health reforms
- furthering research about health care in the state or the health of the state's population.

In this updated report, we reviewed the legislation or regulation creating each existing APCD and that of California's APCD, which is currently in implementation. In Table 2.1, we summarize the goals of the APCDs that were mentioned by each state's legislation. In creating APCDs, states' most-cited goals were to promote price transparency and facilitate reporting of utilization, spending, and quality data. For example, Connecticut's legislation states that a goal of the APCD is to provide data that allow "consumers to make economically sound and medically appropriate health care decisions" (State of Connecticut, Public Act No. 12-166, 2012). Arkansas' act states: "Arkansans face a challenge finding reliable, consumer-friendly information on healthcare utilization, quality, and pricing," pointing to a goal of increased access to information on health care services (State of Arkansas 90th General Assembly, 2015).

Other commonly mentioned goals include measuring quality of care, improving population health, and reducing or controlling the growth in costs of health care. These three functions are crucial to promoting the "Triple Aim" of "improving the experience of care, improving the health of populations, and reducing per capita costs of health care," a widely cited schema for guiding health care reform in the United States (Berwick, Nolan, and Whittington, 2008, p. 759).

A review of state laws provides an incomplete picture of why states choose to create APCDs. For Kansas, Maryland, New York, and Utah, the authorizing legislation focused on the implementation of the APCD. In these states, if any goals identified in our rubric were mentioned, they were most likely to relate to ensuring privacy.

To supplement the information contained in the actual laws, we also examined news articles written around the time of passage that might provide additional insight into the stated goals of the APCD. This was particularly valuable in states where the legislation itself did not discuss the goals. To be included, the article needed to point to the goals as expressed by the legislation or the legislators. The total number of states in which each goal was mentioned in a news article is reported in the final row of Table 2.1. We found a similar distribution of states' goals in newspapers as in the state laws. However, there was not perfect overlap; some goals were mentioned in news articles and were not directly referenced in the actual legislation. Table C.2 in Appendix C provides detailed information about the news articles reviewed.

Whether APCDs have achieved their goals and have achieved a positive return on investment is hard to ascertain because these returns accrue to many different groups. In what follows, we discuss some of the ways in which APCDs have affected policy and how APCDs have been used in research to point toward the benefits of implementing them.

Table 2.1. Goals for State APCDs Mentioned in Authorizing Statutes by State or News Articles

State	Reporting Utilization, Spending, and Quality	Facilitating Price Transparency	Measuring Quality of Care	Improving Population Health	Reducing or Controlling the Growth of Costs	Supporting Health System Reform or Change	Evaluating State Health Reforms	Furthering Research	Ensuring Privacy	Evaluating Disparities
Arkansas	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
California	No	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes
Colorado	Yes	Yes	Yes	Yes	No	Yes	No	Yes	No	No
Connecticut	Yes	Yes	Yes	Yes	Yes	No	No	No	No	No
Delaware	No	Yes	Yes	Yes	Yes	Yes	No	No	No	No
Florida	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	No
Kansas	No	No	No	No	No	No	No	No	No	No
Maine	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
Maryland	No	No	No	No	No	No	No	No	Yes	No
Massachusetts	Yes	Yes	No	No	Yes	No	No	No	No	Yes
Minnesota	Yes	Yes	Yes	Yes	No	Yes	Yes	No	No	Yes
New Hampshire	No	Yes	No	No	No	No	No	No	Yes	Yes
New York	Yes	No	No	No	No	No	No	No	Yes	No
Oregon	No	Yes	No	No	Yes	No	Yes	Yes	No	No
Rhode Island	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	No	No
Utah	No	No	No	No	No	No	No	No	No	No
Vermont	Yes	No	Yes	No	No	No	No	Yes	Yes	Yes
Virginia	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	No
Washington	Yes	Yes	No	Yes	Yes	No	No	No	No	Y
Total in laws	12	13	10	11	11	8	5	7	7	6

State	Reporting Utilization, Spending, and Quality	Facilitating Price Transparency	Measuring Quality of Care	Improving Population Health	Reducing or Controlling the Growth of Costs	Supporting Health System Reform or Change	Evaluating State Health Reforms	Furthering Research	Ensuring Privacy	Evaluating Disparities
Total in news articles	13	17	9	8	9	4	4	6	5	3

SOURCES: State of Arkansas 90th General Assembly, 2015; State of California, 2018; General Assembly of the State of Colorado, 2010; State of Connecticut, 2012; General Assembly of the State of Delaware, 2016; Florida Legislature, 2016; Kansas Legislature, 2012; Maine Legislature, 1995; Code of Maryland Regulations, 1996; The General Court of the Commonwealth of Massachusetts, 2012; Minnesota Legislature, 2008; The General Court of New Hampshire, 2003; New York Codes, 2017; Oregon Legislative Assembly, 2009; Rhode Island General Laws, 2008; Utah Office of Administrative Rules, 2009; Vermont General Assembly, 2007; Virginia Acts of Assembly, 2012; Washington State Legislature, 2014. See Appendix C for further details on news articles.
NOTE: “Yes” = goal was mentioned in authorizing statute. “No” = goal was not mentioned in authorizing statute.

How APCD Analyses Have Informed Public Policy

Beyond informing specific research studies that might have important policy implications, APCDs have informed public policy and helped individuals and employers make purchasing decisions in recent years. This section provides some examples.[5]

Online Comparison Tools

Price transparency reporting has been promoted as a tool to curb rising health care spending and empower consumers to compare prices before making health care purchasing decisions. States have developed websites to help consumers compare prices. State transparency websites that lack APCD data often report comparisons based on only Medicare inpatient claims (Kullgren, Duey, and Werner, 2013), which have limited variation in prices and limited relevance to non-Medicare patients or those seeking nonhospital care.

In recent years, some states have addressed this gap by developing online comparison tools for consumers using APCD data. Examples include online tools from Colorado's Center for Improving Value in Health Care (CIVHC) (CIVHC, undated-a), New Hampshire's NH HealthCost (NH HealthCost, undated), and Maine's CompareMaine (Maine Health Data Organization and Maine Quality Forum, undated).

Research on price transparency tools based on APCD data and other sources of data has shown that a small but nontrivial percentage of patients will use price comparison tools for health services when they are available (Sinaiko, Kakani, and Rosenthal, 2019; Tu and Lauer, 2009; Whaley et al., 2014). Consumer-facing price transparency could modestly reduce the price of some services, but the effectiveness of transparency as a cost-control tool is limited by low consumer use of transparency information and the wide variety of services that are not "shoppable" (e.g., emergency care) (Brown, 2019; Frost and Newman, 2016). Larger cost savings might be achievable through employer use of price transparency tools; for instance, in developing their provider networks (Liu et al., 2021). Large, self-funded employers also might be able to use price transparency tools to negotiate better rates for certain services. In fact, this was an explicit motivation of RAND's hospital price comparison work, which combines claims from self-insured employers, APCDs, and health plans (White and Whaley, 2019). Colorado's CIVHC is currently facilitating these practices by providing standard or customized reports that are available for employers to purchase (CIVHC, undated-c).

Identifying Sources of Growth in Health Care Spending

States have used APCDs to identify areas of disproportionate increases in health care spending. For example, Washington's Office of the Insurance Commissioner recently published

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[5] The ACPD showcase inventories a wide variety of use cases (APCD Showcase, undated).

a report detailing sources of per-member, per-month spending changes. The report found that, out of four service types examined (inpatient services, outpatient services, professional services, and prescription drugs), inpatient services had the largest price-per-service–percentage increase, while prescription drugs had the highest overall percentage increase (Office of the Insurance Commissioner, Washington State, 2022). Similarly, the Oregon Health Authority releases annual reports that use APCD data to identify specific services with the largest percentage cost increases within different service types, such as outpatient surgical procedures, procedures relating to pregnancy, and diagnostic imaging and testing procedures (Oregon Health Authority, Office of Health Analytics, 2021).

Pharmaceutical Prescribing Patterns and Costs

APCDs have been used by several states to study pharmaceutical prescribing patterns and costs, including prescription opioid use. Although an important limitation of APCDs is that not all prescriptions are paid for with insurance, APCDs do typically include prescription drug coverage. Massachusetts used its APCD to produce a series of reports comprehensively documenting prescription drug spending by drug class and by specific drugs, including an interactive dashboard allowing payers and policymakers to monitor trends in utilization and spending at a highly granular level. The New York APCD was used to test whether payments to physicians from opioid manufacturers were associated with higher rates of opioid prescribing, providing policymakers with information that could help inform regulation of interactions between drugmakers and physicians.

Quality Measurement and Improvement

States have used APCDs to measure and improve different aspects of quality of care. For example, a recent report by the Minnesota Department of Health used APCD data to measure rates of blood pressure medication nonadherence by demographics and geography (Minnesota Department of Health, 2021). The report also outlines recommended strategies that individuals, providers, pharmacists, and payers can use to improve adherence.

Another example is the Virginia Center for Health Innovation, which has created a dashboard to help identify rates of low-value services administered in the state (Virginia Center for Health Innovation, 2021).

Legislation

Analysis of APCDs has also directly informed or has been used to enforce legislation seeking to address surprise billing, control overall health care spending, lower the price of insulin, and ensure network adequacy.

Surprise Billing Legislation

Several states have passed legislation to limit the impact on consumers of unanticipated out-of-network billing. For example, Colorado Statute 12-30-113 is intended to protect consumers from surprise out-of-network bills. This legislation sets maximum rates for out-of-network services and uses the Colorado APCD to set benchmarks. Washington and Maine passed similar legislation in 2020 (WA ST 48.49.04; ME ST § 4303-E). Both the Washington and Maine statutes note that arbitrators may request APCD data to establish reasonable payment amounts to resolve disputes between insurers and providers over out-of-network bills. Virginia passed similar legislation in 2020 that is specifically focused on out-of-network emergency services (VA S.B. 172). The legislation notes that the Virginia APCD will be used to set benchmark prices for emergency services.

The federal No Surprises Act, which took effect in January 2022, prohibits insurers from billing enrollees above the median in-network cost-sharing rate for emergency services or for ancillary services from out-of-network providers delivered at in-network facilities (U.S. House of Representatives, 2019). For nonemergency care, out-of-network providers must also notify patients that they are out of network and obtain their consent in writing at least 72 hours prior to service delivery. Although the legislation uses the insurer's median in-network contracted rate as a primary benchmark, it also notes that another database, such as a state APCD, could be used if the insurer does not have sufficient information to calculate a median rate. In implementing the law, HHS will defer to a state's existing law and patient-provider dispute resolution process if the state's law meets standards that are as stringent as the federal law's minimum requirements. The No Surprises Act's provisions apply where states lack authority (e.g., ERISA plans).

Legislation Encouraging the Use of Less Expensive Care Settings

APCDs influenced a 2019 Colorado statute requiring freestanding emergency departments (FSEDs) to explicitly disclose to patients that their facilities are intended to provide care for only emergency medical conditions and are not a primary or urgent care provider. FSEDs are increasingly common in Colorado (Herscovici et al., 2020) and are often designed to look like urgent care centers, but they charge much higher prices (Bucciarelli et al., 2015). The statute on required disclosures was motivated in part by an analysis of Colorado APCD data, which found that FSEDs were routinely used to provide nonemergency services (CO ST § 25-3-119, 2019).

In another example from Colorado, the Primary Care Payment Reform Collaborative was established by Colorado Statute 10-16-150 in 2019 to "develop recommendations and strategies for payment system reforms to reduce health care costs by increasing utilization of primary care." Using the Collaborative's recommendations, the Colorado Division of Insurance mandated targets for the proportion of expenditures allocated to primary care for private health insurers operating in Colorado starting in 2022. The compliance of insurers with these mandates will be evaluated using Colorado APCD data.

Proposed Legislation to Lower Insulin Prices

Citing APCD data, states have proposed legislation to control insulin prices. In 2019, Washington proposed creating a central insulin purchasing program with the goal of leveraging buying power to lower the price of insulin (Washington S.B. 6113, 2019). This proposed legislation was inspired, in part, by an analysis of the Washington APCD that found large increases in the price of insulin paid by insurers and in out-of-pocket costs for patients. Minnesota also proposed legislation in 2019 to authorize the Commissioner of Health to review costs for insulin products sold in Minnesota, determine whether the costs are excessive, and, if necessary, set a maximum level of reimbursement (Minnesota Senate, H.F. 284, 2019). This proposed legislation notes that the commissioner may analyze Minnesota APCD data to make these determinations.

Network Adequacy

The Patient Protection and Affordable Care Act requires that individual and small-group health plans sold in the Marketplace meet network adequacy standards, meaning that enrollees must have sufficient access to in-network providers to receive care without "unreasonable delay" (National Association of Insurance Commissioners, undated). In 2018, New Hampshire strengthened its network adequacy law and began analyzing APCD data to ensure that beneficiaries had adequate access to a variety of services. Analyzing claims data allowed the state to assess adequacy based on actual service volumes, an advance beyond simply tallying in-network providers (N.H. Code Admin. R. Ins 2701.11, 2018).

Research on the Uses of APCDs

In addition to the examples cited earlier, in which APCDs have been used to inform or implement state health policy, academic research using APCD data has played an important role in advancing some of the goals set out for APCDs—especially understanding population health and evaluating the impacts of policy and reforms. Access to APCD data has unleashed an impressive degree of innovation, as evidenced in our annotated bibliography (see Appendix B), which includes 68 studies using APCD data published from 2016 to April 2021.

Many of the research use cases with especially high potential for public health or economic impacts often demand more of the data than simpler applications, such as price benchmarking, and require specific design choices up front to support those use cases. Examples include research on the opioid crisis (Hallvik et al., 2021), cancer care (Garvin et al., 2019), insurance dynamics under the Affordable Care Act (Gordon et al., 2019b), or the cost implications of provider market structure (Brot-Goldberg and de Vaan, 2019). Because APCDs are typically updated within a few months of claims, they are well suited to studying emergent situations, including the COVID-19 pandemic. APCDs were used to study changes in the use of telemedicine during the pandemic (CIVHC, undated-b) and impacts of the pandemic on geographic disparities in well-child visits (DeGuzman et al., 2021). Many of these studies would be impossible without the inclusion of longitudinal patient identifiers or direct identifiers for patients and providers that enable linkage to outside databases.

As shown earlier in Table 2.1, policymakers in most states had a wide variety of goals in mind when creating APCDs. Even with this breadth of objectives, the full range of use cases is likely impossible to anticipate at the time an APCD is established, and design choices that are focused too narrowly on specific use cases could tie the hands of policymakers and researchers in the future. We discuss the potential for design choices to inadvertently limit the usability of APCD data at length in Chapter 4.

History of State APCDs

Maryland created the first APCD in 1998 to support narrowly defined regulatory activities related to costs and efficiency (APCD Council, undated-b). Maine's APCD, which was established in 2003, is considered to be the first to operate under the model that has become most common: State legislation requires nearly all private payers to submit data on claims and enrollment, which are then used to support a broad variety of analyses related to health care costs and utilization. Maine legislators sought to "create and maintain a useful, objective, reliable, and comprehensive health information database that is used to improve the health of Maine citizens and to issue reports" (Maine Legislature, 2021). Additional states began implementing APCDs in the years that followed.

States differ in the sources of funding used to develop and maintain the APCDs. These sources might include state appropriations, data user fees, or fees collected from payers or providers (Commonwealth Fund, 2020). Thirteen states received grants from the Center for Consumer Information and Insurance Oversight in 2013 as part of the ACA to support the enhancement or development of their APCDs (State Health Access Data Assistance Center, 2014).

Today, 18 states have mandatory APCDs (with statutorily mandated reporting from covered payers), an additional seven have voluntary APCDs without a reporting mandate (and eighth state Washington has both voluntary and mandatory efforts),[6] two states with voluntary efforts are currently developing mandatory efforts, and an additional six are currently developing APCDs (for a total of 8 that are developing APCDs) (APCD Council, undated-a). Table C.1 in Appendix C shows additional information about these APCDs, including the year of formation. Figure 2.1, which is based on the state data from the APCD Council, depicts the states that currently have an existing mandatory APCD, a mandatory APCD in implementation, or an existing voluntary effort.

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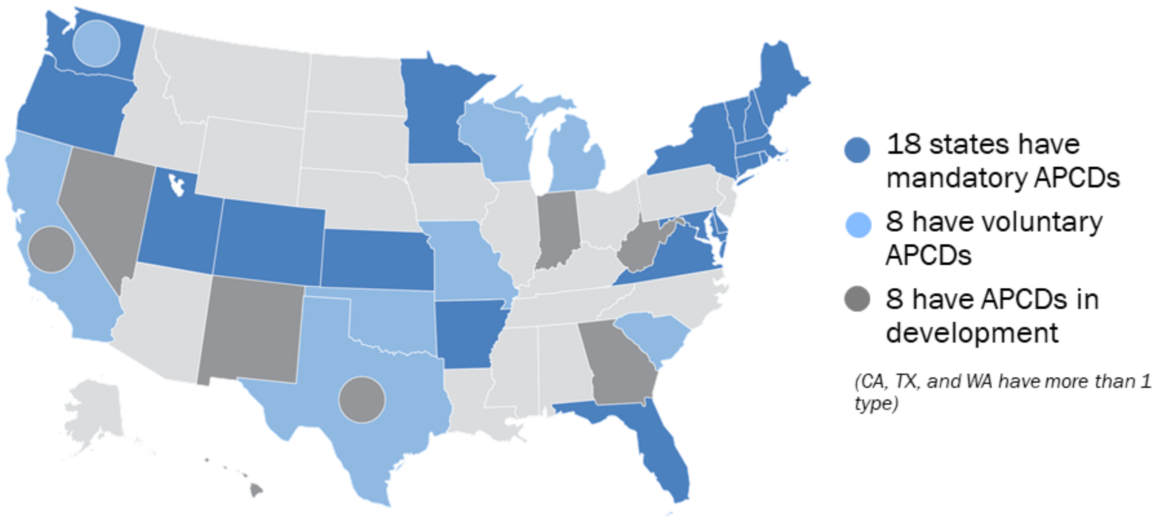
[6] California, Washington, and Texas have both voluntary and mandatory efforts. Also, at the time of data collection for this report, Florida's APCD was classified by the APCD Council as in development, but it has been reclassified as an existing mandatory APCD.

Figure 2.1. State APCD Implementation as of March 10, 2022



APCDs are typically implemented through legislation requiring payers in the state to submit data. However, in a few states, these are voluntary efforts. Each state sets different rules about which payers must submit data and which are exempt from data submission based on the number of lives they cover. Although APCDs capture similar information from payers, there are key differences in the extent to which public payers are included with commercial payers, the availability of data for longitudinal linkage across payers, and the availability of data to independent researchers.

Table C.1 in Appendix C provides information about key submitters to state APCDs. An important difference across states in the regulations that created their APCDs is the inclusion or exclusion of public payers. We distinguish between payers and submitters as follows: Payers represent those organizations that pay for health care, while submitters are those organizations that are required to submit to the APCD in their state and might not include all payers in a state. For most of the remainder of this report, we focus on submitters rather than payers. Some states, such as Maryland, collect data from only private payers and do not include data from state Medicaid programs in their main APCD databases. In these states, APCDs can be used only to study private coverage without further application to the state Medicaid agency. Often, submitters include Medicare Advantage encounters in their submissions, but several states do not include data from fee-for-service Medicare, which is collected by the federal Centers for Medicare & Medicaid Services (CMS). Five states exclude fee-for-service Medicare data, and one excludes Medicaid data; however, other states may require an additional application to access these data.

Gobeille v. Liberty Mutual Insurance Company and the Current Status of ERISA Plans in APCDs

In March 2016, the U.S. Supreme Court issued a decision in *Gobeille v. Liberty Mutual Insurance Company* that substantially changed the nature of state APCDs. As noted earlier, *Gobeille* held that self-insured employers and third-party administrators operating health plans regulated under ERISA could not be compelled by state governments to submit data to APCDs.

The impact of the *Gobeille* decision on the completeness of APCD data is substantial because ESI is the most widespread coverage source in the United States and the majority of workers with ESI coverage are enrolled in self-insured plans. To provide context, Table 2.2 reports the distribution of health insurance coverage by source of coverage for the U.S. civilian noninstitutionalized population as of 2019. At that time, 55 percent of the U.S. population was covered by ESI, and 60 percent of nonfederal civilian enrollees in ESI were enrolled in self-funded plans (AHRQ, Table XI.B.2.b.(1) Percent of Civilian Enrollees That Are Enrolled in Self-Insured Plans at Civilian Establishments That Offer Health Insurance by Private and State/Local Government Sectors and Census Division: United States, 2019). Under the assumption that the same proportion of covered dependents was enrolled in self-funded plans, these estimates would imply that 33 percent of the civilian noninstitutionalized population had self-insured ESI coverage in 2019.[7]

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[7] At the time of writing, the most recent available year of Medical Expenditure Panel Survey Insurance Component (MEPS-IC) data was 2020. The proportion of nonfederal civilian enrollees in ESI who were covered by self-funded plans has ranged between 59 percent and 61 percent in each year from 2015 to 2020 (AHRQ, undated).

More-timely data on the proportion of ESI enrollees covered by self-insured plans is available from the Kaiser Family Foundation's (KFF's) annual survey. KFF's 2021 survey suggests that an estimated 64 percent of workers covered by ESI were enrolled in self-funded plans (Claxton et al., 2021). KFF might report a higher rate of self-insured enrollees than MEPS-IC because the KFF survey excludes very small private-sector employers: The KFF survey targets "private and non-federal public employers with three or more workers," whereas the MEPS-IC includes one- and two-employee firms (Claxton et al., 2021; Davis, 2021).

Table 2.2. Health Insurance Status and Sources of Coverage, 2019

	Proportion of Population Covered
Total with any private health insurance	67%
ESI	55%
Direct-purchase	13%
TRICARE	3%
Total with any public health insurance	35%
Medicaid	20%
Medicare	18%
VA care	2%
Total with any insurance	91%
Uninsured	9%

SOURCE: Data are from the American Community Survey, Table HI05_ACS. Health Insurance Coverage Status and Type of Coverage by State and Age for All Persons (U.S. Census Bureau, 2019).
NOTES: This table reproduces U.S. Census Bureau estimates of the proportion of the civilian noninstitutionalized population with health insurance coverage by source in 2019. VA = U.S. Department of Veterans Affairs. The TRICARE category includes "TRICARE or other military health care." The VA care category encompasses "VA (including those who have ever used or enrolled for VA health care)." The total with any private health insurance category includes people with any coverage from ESI, direct-purchase, or TRICARE. The total with any public health insurance category includes people with any coverage from Medicaid, Medicare, or the VA. Uninsured includes people with none of the listed sources of coverage at the time the American Community Survey was answered. Coverage sources are not mutually exclusive.

The inability of state APCDs to require submissions from self-insured ERISA plans represents a potentially significant weakness for APCDs. In the absence of a federal requirement, some state APCDs have had to rely on voluntary data submissions from self-funded ERISA plans, while others have stopped collecting any data from ERISA plans. The completeness of voluntary ERISA plan reporting across states is not systematically documented and varies substantially across states where such estimates are available: We discuss available estimates in Chapter 4. The voluntary nature of these submissions represents an important challenge for research, benchmarking, and price transparency because ERISA plans represent a large portion of the ESI system. In many cases, these plans do not submit data to APCDs, which limits the representativeness of APCD commercial insurance data.

It is important to note that not all self-funded plans were affected by *Gobeille*; self-funded employee health coverage offered by state and local governments or by churches is regulated under state law rather than ERISA. Because ERISA regulates essentially all self-funded plans at private-sector employers, however, *Gobeille* significantly limited the potential completeness of APCD data for the ESI sector. The proportion of self-insured enrollees in ERISA plans (as opposed to self-insured non-ERISA plans that are still required to submit data to APCDs) is not readily available in most states. Estimates that we found for two states suggest that the size of the population excluded from APCDs because of *Gobeille* might vary widely. In Maryland, where the APCD website states that ERISA plans have not been collected since *Gobeille*, the state reports that the APCD captures 25 to 30 percent of the self-insured market, suggesting that approximately 25 to 30 percent of self-insured enrollees in Maryland are in non-ERISA plans.[8] In contrast, the APCD Council estimated that 45 percent of self-insured enrollees in New Mexico were covered by non-ERISA plans in 2015. Comparable information from other states was not readily available.

One of the important goals of APCDs is to further research and improve population health. However, because APCDs do not include all individuals in a state, there are potentially interesting topics that cannot currently be addressed using APCD data. Extrapolating from APCD data to draw conclusions about population health warrants particular caution. Using APCDs for public health surveillance activities might not be feasible when segments of the insured population, such as individuals covered by ERISA plans and the uninsured, are missing. For example, in the case of the COVID-19 pandemic, ERISA plan enrollees and the uninsured likely would have had different risks of exposure than other populations. It is too early to know how the SAPCDAC's recommendation of a standardized reporting format for ERISA will encourage greater participation in state APCDs and allow greater representation of the insured population.

Furthermore, the exclusion of large segments of the population makes it more difficult to follow individuals over time as they move across insurers and generally makes it impossible to distinguish between individuals who move from one insurance program (such as Marketplace or Medicaid) to uninsured and those who move to a nonsubmitting ERISA plan. Even when several ERISA plans participate, it is possible that participation might be driven by unobserved factors that might also be associated with changes in plan offerings, enrollment, or health care prices, thereby still limiting the representativeness of the APCD's ERISA plan data. It is possible, for instance, that an employer cutting costs because of business challenges or changes in management might simultaneously reduce the generosity of coverage and stop submitting APCD data. Exclusion of these groups poses a challenge to the interpretation of research findings because there might be unobservable differences between self-insured and commercially insured employers or between ERISA plans that voluntarily submit and those that do not voluntarily submit (Fiedler and Linke Young, 2020).

We were able to gather only limited information about the current status of voluntary ERISA plan submission in the states; evidence that was available is discussed Chapter 4. Regardless of exactly how many ERISA plans currently submit data to the states, our review of the goals, use cases, and research applications of APCDs indicates that many of the public policy goals given for APCD data would be advanced significantly by greater ERISA plan participation. Before discussing the implementation challenges currently faced by APCDs, we present an overview of

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[8] Further analysis would be needed to determine whether the proportion of self-insured enrollees covered by non-ERISA plans in Maryland is representative of that in other states (Maryland Health Care Commission, 2022).

the current landscape of state APCD data submission processes, submission formats, and access policies in Chapter 3.

3. The Current Landscape of Data Submission and Access Policies

Although the history, goals, and use cases of APCDs are similar across states, the details of implementation vary. In this chapter, we provide basic information about how state APCDs are structured, what information they collect, and how they can be accessed by analysts. This chapter also describes where there are similarities across states and where differences across states are more pronounced. When possible, we compare design features observed among state APCDs with the APCD Council's CDL. By design, the CDL reflects common design features that are judged to be widely compatible with states' current practices, and thus can be viewed as a frame of reference for our findings on practices observed in the states. The CDL is also an interesting frame of reference because it has been recommended by the SAPCDAC as the format for voluntary ERISA plan submissions.

To address these goals, our team conducted desk research to document the features of state APCDs: We examined the websites of the 18 existing state APCDs (as of the time of data collection) and one APCD under development (California) to better understand the current landscape of data reporting guidelines, file structures, key data elements, and data access procedures. In some cases, we spoke with representatives of state APCDs to confirm or clarify information that was not easily found on state websites. We did not work directly with the APCD data from these states, so did not confirm these findings in the data.

We developed a comprehensive rubric in consultation with ASPE to collect and code these data. Our review allowed us to confirm the existence of information about an APCD, but we could not confirm the absence of information. For example, we investigated whether it was possible to link family members on the same insurance plan. Some states explicitly note that this is possible; however, in other states where it is not explicitly stated, it might still be possible. We developed the rubric in Microsoft Excel to document the specific characteristics of each APCD. The sections and tables in this chapter largely align with the rubric we used to collect data and they provide counts of the number of states where we could document the adoption of specific characteristics. We focus on

- data submission guidelines that describe how data are submitted
- file structure that describes the overall set of files collected and how they are organized
- content collected in enrollment files, which are one of the key file types contained in APCDs
- content collected in claims files, another key file type contained in APCDs
- patient and provider identification information, which is necessary for many use cases and used across files
- data access procedures.

In addition to reviewing existing APCDs, we reviewed the CDL where appropriate. We describe the CDL further in the box. Unless otherwise noted, we exclude New York and Kansas from our summary tables because neither state is actively providing public information about its APCD at this time. As a result, a total of 17 states are included in our review.

Common Data Layout

In an effort to help inform and promote greater standardization in state APCD data, the APCD Council developed the CDL, which is intended to capture common practices among states in data submission formats and offer a template for new APCDs. Beginning shortly after the *Gobeille* ruling in 2016, the APCD Council led an extensive review of data submission formats at all existing state APCDs. The goal was to identify a potential common format that could reduce the burden faced by submitters who must submit to multiple states, especially ERISA plans, and to make cross-state comparisons more feasible.

To develop the CDL, APCD Council analysts cross-walked and compared the data submission formats from all existing state APCDs to identify which features—in terms of file structure, included data elements, and data formats—were widely shared across states. After the APCD Council developed an initial proposal for the CDL, all data elements were reviewed with states, vendors, and submitters to understand the relevant use cases and other arguments for or against inclusion. The CDL was designed to capture common practices among states and offer a template for new APCDs. The first version of the CDL was published in December 2018, and the current version was released in July 2021. The CDL has changed over time to reflect the evolution in use cases and data availability. The CDL lays the groundwork for potential cross-state comparisons or linkages.

Developing the CDL was feasible because, despite differences in state-specific formats, many states already required a similar structure for data submissions from submitters. At this point, no APCD has switched from a previously developed data layout to the CDL; one likely reason for this is that modifying the data submission requirements for APCDs that are already operating would be costly. However, the authorizing legislation for the recently established Virginia APCD instructs the APCD administrator to use the CDL, and similar approaches could be taken in other states currently developing APCDs (Code of Virginia §32.1-276.7:1. All-Payer Claims Database created; purpose; reporting requirements). The California APCD will also be implemented with the CDL. The SAPCDAC recommended the CDL as a standardized format for submission of data for ERISA plans to APCDs (DOL, 2021). Furthermore, the SAPCDAC acknowledged that states with a different reporting format might need time to change their reporting formats. This would require most states to make some changes to their reporting formats, although the changes required are likely to differ from state to state.

Data Submission Guidelines and Procedures

States differ in their data submission guidelines and procedures. These differences vary from the frequency and lag of data updates to the file transfer technology used. Table 3.1 summarizes our findings. In each row of the table, we provide a summary question that describes one element of the rubric we used for coding information available about each APCD; we then provide the number of states for which we were able to obtain information to answer that question. We also provide a comparison with recommendations from the CDL. For example, the second row, "Does the APCD use an integrated data system to track Medicaid or Marketplace coverage?" provides information about the number of states that use an integrated data system that links directly with Medicaid or Marketplace regulators to track coverage. In this case, we were able to document this type of data system for three states. This is not part of the CDL specifications.

Table 3.1. Data Submission Guidelines and Procedures

Question About APCDs	Number of States Answering Yes (additional details)	Relevant Specification from CDL
Does the state specify the file transfer technology payers use to submit data?	8	None
Does the APCD use an integrated data system to track Medicaid or Marketplace coverage?	3	None
Does the APCD specify how frequently data for enrollment file are collected?	12 (Enrollment file collection frequency ranged from monthly to yearly)	Reporting periods for member eligibility files should be no longer than six months
Is the data lag for the enrollment file (between policy start date and completion of cleaned file) specified?	6 (Enrollment file lag ranged from 1 to 12 months)	None
Is the data lag for the claims data specified?	10 (Claims data lag ranged from 1 to 12 months)	None
Are claims data updated or refreshed after initial submission?	9	Claims should be refreshed after initial submission

NOTE: This table notes how many states (out of 16 states with currently existing APCDs and one state in implementation) clearly answered the question listed on their website so that answers were readily available through our desk research efforts. Two states with existing APCDs (Kansas and New York) were excluded from the analysis because of a lack of publicly available information. We list the number of states for which we could confirm the APCD's policy for each characteristic; thus, each represents a lower bound.

Only eight states provided clear information about their file transfer technology on their websites. However, all states operating APCDs, with the exception of New York, use the same file transfer technology (Secure File Transfer Protocol [SFTP]). Although it is excluded from Table 3.1, the relatively new York APCD has taken a very different approach to data submission and file transfer technology from that of other states. Rather than periodically submitting flat files covering all enrollees and claims from a given period, submitters use a transaction-based Electronic Data Interchange (EDI) system to transmit records on a more continuous basis; EDI transaction-based data formats are widely used to transmit data for claims processing and other business purposes. The Accredited Standards Committee X12 and the National Council for Prescription Drug Programs (NCPDP) developed the EDI standards adopted by New York to capture data that are similar to those in the CDL, so it is likely that the research files produced in New York will have substantial overlap with those of existing APCDs in terms of included variables. Although file transfer technology is not mentioned in the CDL, it was mentioned by the SAPCDAC because differences across states can create burdens for submitters who operate in multiple locations.

Another key area of difference is the frequency of data collection and the lag between (1) claims being filed or enrollment changes occurring and (2) data being made available for use. Seven states provided information on the time between care being received and data being available in the APCD (the lag) for claims data ranging from one to six months. Three states did not provide specific periods but give some information. APCDs also pointed out that it can take several months for claims to be adjudicated and finalized, that claims can be updated in the APCD after initial data are submitted, and that lags can vary by insurer.

Content Collected in State APCD Enrollment Files

As intended by its designers, the CDL's format is consistent with the reporting structure of most states. Most states have an enrollment file that contains information about each enrollee covered by a payer in a given period, regardless of whether they have any claims. As noted in Chapter 2, the inclusion of data on enrollees who do not use any care that results in claims is an important feature distinguishing APCDs from some other multipayer databases that observe only individuals who receive certain types of care. Without information on the number of individuals enrolled at any given time, correct denominators for utilization rates cannot be determined.

In general, the basic structure of an enrollment file is a list of individuals covered by a payer in a given period (typically one month), along with information about the characteristics of the individuals' coverage and some information about the characteristics of the individuals. In a small number of cases, these files also contain information about disenrollment; in other cases, an individual's disenrollment might be inferred from the absence of an enrollment record. Table 3.2 summarizes the structure and data about enrollment contained in enrollment files. Although the type of plan and source of coverage are included in all states, other more-detailed information, such as Medicaid eligibility group or premiums, is more mixed.

One key difference is whether enrollment files are monthly or spell-based. A monthly file would include an observation for each person-month of coverage. Thus, an individual who was covered for two calendar years would have 24 records in the monthly file, one for each month. A spell-based enrollment file would have one record for the entire period of enrollment. Both types of files could include the start and end dates of coverage. Most states give the exact date for start and end of coverage, but two report only the month. Only two states reported providing information about the reason for the end of coverage, but this did not include moving to another state.

Table 3.2. Structure and Content of Enrollment Files

Question About APCD	Number of States Answering Yes (additional details)	Relevant Specification from CDL
Is type of plan, plan design, and/or plan name (e.g., EPO, HMO, POS) provided?	17	Required field
Is source of coverage identified in enrollment file (e.g., Medicaid/ESI/Marketplace) provided?	16	Required field
Does enrollment file include people who do not file claims?	13	Required field
Is coverage start date reported?	15 (13 states give exact date, 2 states give month)	Exact coverage start date required
Is coverage end date reported?	14 (12 states give exact date, 2 states give month)	Exact coverage end date required
Is reason for coverage end reported (e.g., failure to pay premium, job separation, other transitions)?	1	None
Is spell-based or monthly coverage specified?	17 (1 state spell-based, 16 states monthly)	Report monthly coverage
Is death observed?	2	None
Is migration (i.e., moving out of state) observed?	0	None
Is institutionalization observed?	2	None
Is exit to different insurance source (or noncovered insurance source) observed?	2	None

NOTE: This table counts how many states (out of 16 states with currently existing APCDs and one state in implementation) clearly answered the question listed on their website so that answers were readily available through our desk research efforts. Two states with existing APCDs (Kansas and New York) were excluded from the analysis because of a lack of publicly available information. We list the number of states for which we could confirm the APCD's policy for each characteristic; thus, each represents a lower bound. EPO = exclusive provider organization. HMO = health maintenance organization. POS = point of service.

Enrollment files also might contain demographic information. Conducting research about many topics—especially population health—often requires detailed demographic data. Although most states collect basic information, such as age and sex or gender, other information is more variable. Table 3.3 summarizes the number of states collecting data on selected sociodemographic characteristics. Limited information is available about such characteristics as income, in part because this is not information that many payers collect. Location can be particularly important for studying health care markets. One state gives three-digit ZIP codes, nine states give five-digit ZIP codes, and four states give nine-digit ZIP codes.

There are two important limitations, which we discuss in more detail in later sections. First, even when data fields are present, the data contained in those fields might be incomplete or inaccurate. Second, although these data are collected by the APCD, their availability to researchers might be restricted. For example, a state that collects nine-digit ZIP codes might require a clearly defined and justified use case to provide nine-digit ZIP codes and might instead provide only three- or five-digit ZIP codes.

Table 3.3. Sociodemographic Data Collection

Question About APCD	Number of States Answering Yes (additional details)	Relevant Specification from CDL
Is any demographic information included (e.g., race/ethnicity, age, sex)?	17	Required field
Is race/ethnicity included?	15	Required field
Is age included?	17 (10 states give date of birth, 2 states give month and year of birth, 4 states give age in years, 1 state gives age groups)	Report date of birth
Is sex or gender included?	17	Required field
Is location of residence included?	14 (1 state gives 3-digit ZIP code, 9 states give 5-digit ZIP code, 4 states give 9-digit ZIP code)	5-digit ZIP code required
Is family structure or coverage tier (e.g., self/self+spouse/self+dependent) included?	13	Required field
Is it possible to link family members on the same plan?	11	Family ID to allow linkage is required field
Is family income included?	2	None
Is poverty status included?	0	None

NOTE: This table counts how many states (out of 16 states with currently existing APCDs and one state in implementation) clearly answered the question listed on their website so that answers were readily available through our desk research efforts. Two states with existing APCDs (Kansas and New York) were excluded from the analysis because of a lack of publicly available information. We list the number of states for which we could confirm the APCD's policy for each characteristic; thus, each represents a lower bound.

Marketplace and Medicaid Information

One area of policy interest is the use of APCDs to study enrollees in Medicaid and Marketplace plans. Table 3.4 presents findings on state practices for collecting information that is specific to Medicaid or Marketplace coverage. In some cases, states collect additional information about enrollment in these plans that can be useful in studying how differences in benefit design or program eligibility might affect enrollees. In the case of Medicaid, for example, the specific program or broad eligibility group might be important for distinguishing between subpopulations with different expected health care needs. Users might also be interested in identifying whether plans are purchased on the private market or through the Marketplace; the policy implications of having nongroup private insurance depend on the source of coverage. These data are all included in the CDL.

Table 3.4. Marketplace and Medicaid Information in Enrollment Files

Question About APCD	Number of States Answering Yes (Additional Details)	Relevant Specification from CDL
Are Children's Health Insurance Plan (CHIP) plans included?	8	None
Are fee-for-service Medicaid plans included?	14	None
Are Medicaid managed care plans included?	12	None
Is information about Medicaid plan or eligibility group (e.g., specific programs, broad eligibility group) provided?	10	Required field
Are Marketplace plans included?	15	None
Is information about source of coverage or how coverage is obtained for individual market or Marketplace plans provided?	12	Required field
Are premium amounts provided?	9	Required field
Is Marketplace metal tier included?	11	Required field

NOTE: This table counts how many states (out of 16 states with currently existing APCDs and one state in implementation) clearly answered the question listed on their website so that answers were readily available through our desk research efforts. Two states with existing APCDs (Kansas and New York) were excluded from the analysis because of a lack of publicly available information. We list the number of states for which we could confirm the APCD's policy for each characteristic; thus, each represents a lower bound.

Content Collected in State APCD Medical Claim Files

In most cases, states' claims files are in alignment with the CDL in terms of the types of medical claims included, but there are differences in terms of the structure of the files. We collected detailed information about the data contained in claims files, which is summarized in Table 3.5. In all states, payers are required to submit enrollment and claims files, and the criteria for who should be included is the same for both files. However, documentation on the types of utilization or claims that must be included was not always easy for us to discern.

Table 3.5. Contents of Claims Files

Question About APCD	Number of States Answering Yes (additional details)	Relevant Specification from CDL
Does claim file include approved claims only (or identify approved claims)?	6	Includes only nondenied claims
Can claim file be linked to enrollment file at patient level?	16	Required to use same beneficiary ID for enrollment and claim files
Are any self-pay claims explicitly included (including co-pays, co-insurance, and amount paid toward deductible)?	8	Required to include co-pay, co-insurance, and amount paid toward deductible
Are prescription drugs included?	17	Required for inclusion
Are inpatient hospitalizations included?	17	Required for inclusion
Are office visits included?	17	Required for inclusion
Are outpatient hospital visits included?	17	Required for inclusion
Are ED visits included?	17	Required for inclusion
Is an out-of-network/balance billing indicator included?	6	Required field
Is a single file used for all medical claim types (e.g., inpatient, outpatient, ER)?	8	Single file for all claim types required
Are multiple files used for different medical claim types (e.g., inpatient, outpatient, ER)?	3	Single file for all claim types required
Are diagnosis codes in separate files?	3	Diagnosis codes are in claim file
Are procedure codes in separate files?	3	Procedure codes are in claim file

NOTE: This table counts how many states (out of 16 states with currently existing APCDs and one state in implementation) clearly answered the question listed on their website so that answers were readily available through our desk research efforts. Two states with existing APCDs (Kansas and New York) were excluded from the analysis because of a lack of publicly available information. We list the number of states for which we could confirm the APCD's policy for each characteristic; thus, each represents a lower bound. ED = emergency department. ER = emergency room.

We found that some states provide two types of useful information in APCDs that might be perceived to be out of scope for an APCD. First, multiple state APCDs collect *self-pay claims*, which are claims for services for which the patient pays the provider something while the insurer pays nothing. Analysts who are interested in out-of-pocket costs are often concerned that self-pay claims are likely to be missing from APCDs. We found that eight states reported that they collect at least some data on self-pay claims (e.g., patient cost-sharing or the amount patients self-pay prior to reaching their deductible) that are submitted to payers. These data will almost certainly be limited to costs that an individual reports to their insurance company (for example, to document costs paid toward an out-of-pocket limit). Out-of-pocket health care costs that are unlikely to result in a claim being filed might not be captured in an APCD. Second, a few states provide information about out-of-network claims and balance billing.

States also differ in the structure of their claims files, which can make working with multiple APCDs particularly challenging for payers who are submitting data and for analysts who are using data. Eight states have a single file for all claim types, while three collect different files for different bill types or split information about procedure and diagnosis codes into separate file submissions.

Patient and Provider Identification

Patient and provider identifiers are critical for several basic functions of an APCD. In particular, they are necessary to link information across files. However, one of the key advantages of APCDs is the longitudinal data that they provide. The ability to follow specific individuals over time, be they patients or providers, requires patient and provider identifiers.

Patient Identification

The CDL requires two levels of patient identifiers: a within-payer identifier and an identifier that can allow an individual to be tracked across payers over time. The former is common for all payers, but the latter is relatively unique to APCDs and is key for specific types of research. Table 3.6 provides summary information about the person identifiers available in the 17 APCDs we reviewed. Several states explicitly do not allow the creation of an identifier that allows following an individual over time. Although the CDL does include a longitudinal identifier, it does not make recommendations about how this should be implemented. States differ in the information they use to create a longitudinal identifier and in their documentation of these efforts. Name, date of birth, and Social Security Number (SSN) are most commonly used to create a longitudinal identifier. Several states use other information, such as telephone number or member and subscriber information. Two states provide a confidence score for their longitudinal identifiers that can be important for evaluating the robustness of research that relies on tracking individuals across payers or over time.

Table 3.6. Patient Identifiers

Question About APCD	Number of States Answering Yes (additional details)	Relevant Specification from CDL
Is it possible to track individuals longitudinally across plans?	14	Recommends including identifier
If imputed, are there flags indicating the APCD's confidence in the imputation?	2	None
Is name used to create person identifiers?	5	None
Is DOB used to create person identifiers?	5	None specified
Is address used to create person identifiers?	3	None
Is SSN used to create person identifiers?	6	None specified
Is gender used to create person identifiers?	2	None
Are any other fields used to create person identifiers?	2	None

NOTE: This table counts how many states (out of 16 states with currently existing APCDs and one state in implementation) clearly answered the question listed on their website so that answers were readily available through our desk research efforts. Two states with existing APCDs (Kansas and New York) were excluded from the analysis because of a lack of publicly available information. We list the number of states for which we could confirm the APCD's policy for each characteristic; thus, each represents a lower bound. DOB = date of birth.

At a minimum, analysts require a unique member ID within a submitter (e.g., Medicare number or insurer-assigned member ID) to link individuals across multiple files, such as linking medical or pharmacy claims to enrollment records submitted in the same month. Although the CDL and state APCDs generally require submission of member ID numbers on all enrollment and claim files, some payers have historically recycled member ID numbers over time. When this occurs, it might not be possible to determine whether multiple records for a given member ID over time belong to the same individual or different individuals. The CDL and state data submission guides now instruct submitters to use an ID that is unique to the person; however, mistakes can still occur.

Member IDs are unique to the submitters and do not allow tracking of an individual across payers, yet many important uses of APCD data demand variables that allow linkage of individuals across submitters and over time. As discussed in greater detail earlier, this can be done with direct identifiers or with an encrypted longitudinal ID assigned by the submitters following an algorithm defined by the APCD. The CDL, following practices in most states, provides for collection of direct patient identifiers, including name, date of birth, residence address, and SSN. States can then use this information to create a longitudinal identifier. This creates risks for patient privacy because personally identifiable information is transferred to additional organizations. A second approach protects privacy but has serious drawbacks. One state provides submitters with a hash function (an encryption algorithm) that assigns unique combinations of last name and date of birth to an encrypted ID, which is transmitted to the APCD in lieu of these direct identifiers.

In practice, there are a variety of problems with this approach. Last name and date of birth are not uniquely identifying—most obviously for twins, but also for individuals with common last names. Rates of false-positive linkages according to name and date of birth are systematically different across racial and ethnic groups. Name change at marriage will also lead to differential accuracy of the longitudinal ID across genders. Although APCD data can be linked to other databases by applying the hashing algorithm to those data sources, the lack of underlying direct identifiers hampers evaluation of data quality. This approach also relies on submitters to apply the hash function correctly; in practice, even large and sophisticated submitters have failed to do so, which can require resubmission of data.

Provider Identification

Being able to identify specific providers is also critical for analyses that are designed to compare payment rates across providers or assess the quality of similar types of providers (for example, managing diabetes patients). Provider IDs can differ across submitters and APCDs. National Provider Identifiers (NPIs) are standardized, publicly available identifiers that are required for any provider billing electronically. NPIs allow providers to self-report specialty type, which is useful for analyses comparing providers of certain specialties.

The NPI has some limitations, however. Although NPIs could be used to identify providers across payers, many APCDs do not require their use, and many private insurers do not use the NPI as an identifier. As a result, provider-level analyses can be challenging in some states. A further challenge is that a single NPI might be used for multiple physicians and providers who bill as part of the same organization. Other information, including state license numbers and provider names, can also be used, but again this information is feasible only if all submitters use these identifiers. Names, addresses, and telephone numbers contained in such provider directories as the National Plan and Provider Enumeration System (NPPES), Medicare Advantage directories from individual health plans, and Marketplace exchange databases are often inconsistently captured or contain inaccuracies. However, information in provider directories might soon improve as the No Surprises Act sets new requirements for plans to regularly update provider directories (U.S. House of Representatives, 2019). The Act also provides additional funding to state APCDs, which they may choose to use to develop centralized provider directories or improve the quality of provider information received. Although the problems associated with identifying providers are not unique to APCDs, they are an important consideration for designing a common data submission format that might be used across multiple states. Our review suggests that states differ in their collection of provider identifiers: Most states collect some provider identifiers, but the number of distinct provider IDs and the level of detail differ across states. Table 3.7 summarizes the provider identifiers available in APCDs.

Table 3.7. Provider Identifiers

Question About APCD	Number of States Answering Yes (additional details)	Relevant Specification from CDL
Are identifiers collected for treating or rendering physicians or health care providers (e.g., NPI, tax ID number)?	15	Require collection of NPI, provider name, and provider address
Are identifiers collected for billing physicians or health care providers (e.g., NPI, tax ID number)?	14	Require collection of NPI, billing provider name or organization name, tax ID
Are identifiers collected for facilities (e.g., AHA hospital ID)?	11	None

NOTE: This table counts how many states (out of 16 states with currently existing APCDs and one state in implementation) clearly answered the question listed on their website so that answers were readily available through our desk research efforts. Two states with existing APCDs (Kansas and New York) were excluded from the analysis because of a lack of publicly available information. We list the number of states for which we could confirm the APCD's policy for each characteristic; thus, each represents a lower bound. AHA = American Hospital Association.

Data Access Procedures

The procedures for outside researchers and analysts to access APCD data also vary from state to state. All but two states reported making data available to researchers outside the APCD organizations, and most states have detailed guidelines for their use. Summary findings from this review are described in Table 3.8.

Table 3.8. Access Procedures and Restrictions

Question About APCD	Number of States Answering Yes (additional details)
Is the APCD data available to researchers outside the APCD organization?	15
Does state have publicly available guidelines or regulations to allow access by researchers?	13
Are local (within-state) partners required to access the APCD?	1
Is access limited to state government contractors?	1
Are there differences in access among government, nongovernment, and academic users?	9
Are there publication restrictions for researchers using the APCD?	6
Are there peer-reviewed publications by academic researchers using state APCD data?	14
Does state provide pricing information for data?	11
Does state provide information on the length of the DUA/license?	2
Is data reuse and are modifications to the DUA possible?	8
Does state provide time frame for data access/acquisition?	5
Is it possible to work with APCD microdata offsite?	6

Question About APCD	Number of States Answering Yes (additional details)
Do data need to be stored on secure server?	4
Do data need to be stored in cold room + de-identified on secure server?	0

NOTE: This table counts how many states (out of 16 states with currently existing APCDs and one state in implementation) clearly answered the question listed on their website so that answers were readily available through our desk research efforts. Two states with existing APCDs (Kansas and New York) were excluded from the analysis because of a lack of publicly available information. We list the number of states for which we could confirm the APCD's policy for each characteristic; thus, each represents a lower bound. DUA = data use agreement.

Overall, nine states have different access rules for government users and nongovernmental or academic researchers. Government users tend to be able to access data from more payers and access more-detailed information than external (e.g., academic, nonprofit, for-profit company) researchers. In Vermont, for example, external users have access to a more restricted data set that does not include Medicare data. And in Washington, government users can access additional identifiers and more-detailed financial information than external agencies.

The data acquisition process can vary from state to state but generally involves completing an application, establishing a data use agreement, and paying a fee. Fees can range from $500 to $87,500 per file, with prices varying depending on numerous factors, such as size and complexity of files, type of organization requesting (for-profit requests typically have a higher cost compared with those of nonprofit or academic requests), and whether it is a new request or a request for additional years of data. Sometimes there are separate charges for claims and enrollment, but usually these are purchased together. Where prices are listed separately, claims data tend to be more expensive than enrollment data. Some states also charge an application fee or a fee for custom reports. Few states provide information on their websites about the length of time (i.e., the term) of the data use agreement, but all of the state APCDs we have worked with set a specific period of time for use of the data in the data use agreement.

Another important area of difference is how data can be accessed. When working with health care data sets more broadly, some sensitive data sets require researchers to store the data in a cold room, on a secure server, in a restricted access data center (such as a Census Research Data Center), or on a secure server hosted by the data provider that can be accessed only by researchers. We found few details on these types of restrictions for APCD data, but this might be attributable to the limited information that is publicly available. Researchers might be informed of additional restrictions on data access during the data acquisition process, and these restrictions might be dependent on the types of data requested. In our experience with working with indirectly identifiable data from state APCDs, the data use agreements contain specific and relatively stringent requirements for data security. For example, restrictions might be placed on keeping files on a password-protected computer or limiting where files are accessed. One state required an interview with the information security team to discuss the data security plan in detail.

Although it is not necessarily documented, our experience also suggests that, out of concern for resident privacy, APCDs will not always make all data available to all researchers. APCDs might require that researchers describe a clear need for particularly sensitive data, such as birthdates or ZIP codes. Without a justifiable need for these data, an APCD could provide data at a higher level of granularity, mask the data, or not release the data. Alternatively, if some variables are particularly important for the research design (for example, specific location), they might provide less detailed information about other variables (such as date of birth). In some cases, data are collected but available only for internal research, not to external researchers.

Nearly all states have data documentation available on their websites, including a data dictionary or codebook. In the past, some states posted current data quality concerns on their websites to allow researchers to take these into account, but we found only one state that was currently doing so.

4. Challenges and Limitations to Success

Although APCDs have great promise, there are potential stumbling blocks to their success. In this chapter, we discuss the challenges to implementation, the need for stakeholder engagement to support successful implementation, and limitations of use of APCD data.

Implementation Challenges

Developing and implementing an APCD brings potential policy benefits, but there are considerable challenges associated with bringing together health insurance claims and enrollment data from multiple submitters. In this chapter, we discuss some of the most notable challenges. Further resources on implementation challenges are listed in Appendix B and, in particular, in Fiedler and Linke Young, 2020; Freedman, Green, and Landon, 2016; Harrington, 2017; and National Association of Health Data Organizations, 2019.

Privacy

APCDs collect Protected Health Information (PHI), so it is critical for states to have a strategy for protecting patient privacy. Decisions about how much information to collect about enrollees involve a trade-off between making the data more usable and increasing the potential harms to patients if a data breach occurs. PHI includes not only direct identifiers but also much of the information about health and health care utilization contained in an APCD.

One strategy that states have used to protect PHI is to create a unique longitudinal identifier that can be included in the research files in place of direct identifiers. The creation of high-quality longitudinal identifiers requires collection of identifying information, including names, dates of birth, and, ideally, SSNs. As described earlier, this can be done by collecting the data directly from submitters and creating a unique identifier in-house. Another strategy reduces privacy risk for state residents by having submitters assign the longitudinal ID to their data prior to submission, using an encryption algorithm provided by the state. The latter method has the advantage of sharing less directly identifiable information but the disadvantage of making it more difficult for APCDs to correct problems in application of the encryption algorithm should they occur and potentially hindering linkage to outside data sources. In practice, there are a variety of problems with this approach. Last name and date of birth are not uniquely identifying—most obviously for twins, but also for individuals with common last names. Rates of false-positive linkages based on name and date of birth are systematically different across racial and ethnic groups. Name change at marriage also will lead to differential accuracy of the longitudinal ID across genders. Although APCD data can be linked to other databases by applying the hashing algorithm to those data sources, the lack of the underlying direct identifiers hampers evaluation of data quality. This approach also relies on submitters to apply the hash function correctly; in our experience, even large and sophisticated submitters have failed to do so, which can require resubmission of data. The accuracy of longitudinal identifiers also involves trade-offs that require deliberation at the design stage. Using SSN and name to create longitudinal identifiers offers more-accurate results than using name only but at the expense of greater risk to privacy. Ultimately, APCDs will contain sensitive information, and careful consideration of privacy issues is necessary. Another strategy is to limit access to identifying information through strict data use agreements (Harrington, 2017).

Issues surrounding the reporting of sensitive health conditions have also emerged. Although the discussion has focused primarily on care for substance use disorders, similar concerns about privacy could arise in other settings. In 2014, independent researchers discovered that CMS had for some time been "scrubbing" claims with substance use disorder diagnoses from their data to comply with privacy regulations issued by the Substance Abuse and Mental Health Services Administration (SAMHSA) (Anthem Public Policy Institute, 2018). Amid rising overdose death rates, this policy severely undermined the usability of claims data for research on substance use disorders and, more generally, threatened the validity of research on a much wider variety of conditions that are correlated with substance use disorders (Roberto et al., 2017). Regulatory changes to address the inclusion of substance use disorder–related information claims were initiated by SAMHSA in 2017, with interim changes finalized in summer 2020. Furthermore, the CARES Act mandated aligning SAMHSA's information exchange requirements with those of HIPAA. A regulation that will do this is under development. However, the implications and changes for state APCDs remain an area of discussion and highlight the importance and challenges of protecting patient privacy around sensitive health care claims.

APCDs must also make similar decisions about provider privacy. If price transparency is a goal and names of providers are not made public, consumers, employers, and payers can determine only where the prices they face fit in the overall distribution of prices. That is, they might compare the prices these individuals have been charged by their providers with those in the APCD to learn whether the provider is relatively expensive, but they would not be able to determine which local providers are less expensive. If the names of providers are made public, this can potentially have an even greater impact on prices as payers and consumers become aware of providers with the highest prices, as in the RAND Hospital Transparency Study (White and Whaley, 2019; Whaley et al., 2020). This study used data combined from APCDs and self-insured employers and health plans to compare prices paid at specific hospitals across the country, highlighting not only differences in prices paid by different payers but also the specific providers with the highest prices. Similar issues could arise surrounding quality transparency.

Data Submission Guidelines and Procedures

Data submission guidelines and procedures must be developed with the engagement of submitters. If submission guidelines are not sensitive to what submitters are able to provide or are not communicated well to submitters, APCDs run the risk of collecting low-quality data. In previous research where we interviewed APCDs and submitters, we found that communication about data expectations was important before initial data submissions and throughout the lifetime of an APCD (Carman, Reid, and Damberg, 2020). In particular, difficult or misunderstood guidelines could contribute to low-quality data. Furthermore, some submitters reported that state submission guidelines do not provide sufficient time to prepare files that are complete (Anthem Public Policy Institute, 2018).

Because each state operates its own APCD, states have largely developed their own data submission guidelines and procedures. Many states work with the same vendors to process their data files, and the development of reporting formats has been informed by widely used claim formats originally developed by CMS or by independent standards bodies, such as X12 (the organization that manages EDI standards). Formats used in many states are broadly similar, but the details often differ and might be shaped by a state's particular primary use cases. Such details include different variable formats (for example, string length), different variable names for similar information, or differences in the data elements being collected. This creates additional burden on payers who operate across states, including multistate ERISA plans.

Collection of Non–Fee-For-Service Payments

APCDs were designed around the collection of claims data, but over time more health care is being provided through non–fee-for-service payment models, including capitation payment and alternative payment models. In 2020, we interviewed states and submitters who were collecting non–fee-for-service payments (Carman, Reid, and Damberg, 2020). Because there are many different models of non–fee-for-service payments, a significant challenge of collecting these data is categorizing payments to understand precisely which services are being paid. Furthermore, the models used in different states can vary dramatically; for example, some states and payers use payments linked to quality and value, others use models built on a fee-for-service architecture, and others use population-based payments (The MITRE Corporation, 2017). As a result, developing a single national standard for non–fee-for-service payments will be particularly challenging. Five states have strategies in place to collect data on alterative payment models. At the state level, developing a model for data collection is less complex because non–fee-for-service payments within a state are less heterogeneous.

Use Cases

When designing and implementing an APCD, use cases should be considered. To justify the significant costs of building and maintaining an APCD, a design that supports many use cases will make the investment more valuable. As states consider how best to implement an APCD, they should keep in mind the use cases that they wish to address and how the design of reporting formats can affect the breadth of potential use cases. Additional investments could open the

APCD up to a much broader set of use cases. Appendix A provides a framework for understanding the data needs for different use cases.

Uniformity of Data Across States

As we showed in Chapter 3, there are significant differences in the data collected and the data structure across states. A more uniform data structure, if adopted widely by states, would help reduce submitter burden and address some of the challenges noted earlier. In discussing APCD data structures, it is important to distinguish between the structure of the files submitted to APCDs (which are affected by the reporting formats submitters are required to use to submit their data, the focus of the SAPCDAC) and the structure of the processed database or the research files available to outside researchers (which is affected by the data model used by a state in structuring its consolidated database). We note that there is ample room for greater standardization of both payer submissions (the inputs to the APCD) and research files (the outputs from the ACPD). Making the data available to researchers more comparable across states will facilitate research comparisons of utilization, prices, and quality of care across states. Development of methods and output data formats to facilitate cross-state comparisons of APCD data is an active area of research (de Jesus Diaz-Perez et al., 2019). The SAPCDAC recommended that ERISA plans submit data using the standardized CDL and that states move to this uniform standard as well. This would involve transition costs in the short term for both states and submitters who are already collecting or submitting data.

Stakeholder Perspectives

APCDs potentially benefit a wide variety of stakeholders, including consumers, employers, providers, policymakers, researchers, and payers. Engaging all of these groups is important to make sure that APCDs can balance the needs of potential users, the interests of payers or other specific stakeholder groups, and the benefits for public health and the economy of better data on health care prices, coverage, and utilization. Involving stakeholders at multiple stages of implementation can help identify and address trade-offs. In this section, we discuss views held by different stakeholder groups (and how they can, at times, be in opposition) and the importance of stakeholder engagement.

Trade-Offs Between Stakeholder Groups

Different use cases can be viewed differently by different stakeholders. Development and operation of an APCD requires a careful balance of trade-offs across stakeholders. A key example is price transparency, which has been emphasized in the state discourse surrounding the creation of APCDs. Price transparency information derived from APCDs can help purchasers, insurers, and third-party administrators negotiate lower prices or implement programs that steer patients toward lower-priced providers. At the same time, a concern expressed by some stakeholders and researchers is that price transparency data could have anticompetitive effects, helping providers negotiate higher prices with payers (Anthem Public Policy Institute, 2018). We note that researchers have differing views on the extent of this concern in health care markets (Sanger-Katz, 2019): The clearest examples of tacit collusion facilitated by price disclosure come from non–health care markets outside the United States (Albæk, Møllgaard, and Overgaard, 1997), and some features of the U.S. health care market (such as staggered price negotiations and data lags) might reduce the scope for such conduct. Some states have taken efforts to minimize the potential for anticompetitive effects of public reports, for example by restricting reporting to information that combines data across multiple payers or reports data with a multiple-month lag.

Researchers and policymakers often hope to have data for a wide variety of use cases, but this can increase the costs associated with creating and maintaining an APCD for states and can increase the burden for submitters. As an example, APCDs are often justified in terms of facilitating scorecards and benchmarking for the public. This typically does not require a longitudinal identifier for patients. However, as has been discussed elsewhere in this report, longitudinal identifiers can increase the potential use cases (Bardach et al., 2017). Creating and maintaining additional information that is necessary for a longitudinal identifier (whether it is created at the APCD or encrypted by the submitter) increases the burden to the submitter. Furthermore, creating additional files that meet the formatting and data quality requirements of an APCD increases the burden for submitters while increasing the value for users.

Partnership with Stakeholders

Partnerships with key stakeholders can significantly improve the value of APCDs. A close partnership between states and users is important and highly beneficial to both parties. Regardless of the data verification processes that states have in place, a user might look at the data in a different way and identify errors that require states to go back to submitters for corrections or to make changes to their data. Many states have introduced APCD user groups that can facilitate discussion among APCD staff, data contractors, and users. Ultimately this give-and-take has helped improve not only the research being done by an individual group but also the overall quality of the APCDs (National Association of Health Data Organizations, 2019).

The perspectives of submitters are likely to be particularly important. In recent RAND work for the Milbank Memorial Fund, we discussed state data collection procedures (Carman, Reid, and Damberg, 2020). We found that open discussions with submitters were crucial to developing submission standards that were feasible, understandable, and not excessively burdensome for submitters. National insurers, in particular, were concerned about difficulties that would arise if submission guidelines varied dramatically from state to state. Stakeholder involvement in designing requirements can build a foundation for future engagement and submitter compliance with guidelines. A report by Anthem Public Policy Institute highlights additional concerns of data submitters, including privacy issues, exclusion of ERISA plans, anticompetitive concerns, data standardization, and data submission concerns (Anthem Public Policy Institute, 2018). We note that states have worked closely with their payer stakeholders to address these issues and implement solutions.

Limitations of Research and Analyses Using APCD Databases

Missing Populations

An important limitation of most APCDs is that they do not capture data on the entire state population. As noted earlier, data from ERISA plans are generally limited or incomplete, and APCDs do not collect any data on the uninsured. In addition to these limitations, APCDs generally do not receive claims or records from some federal payers. such as TRICARE or the Federal Employee Health Benefits Program (FEHBP). APCDs also do not receive patient records from federal health systems that are important sources of care for specific populations, including the Veterans Health Administration (VHA) and the Indian Health Service (IHS). Claims paid by workers' compensation, auto insurance, and other property or casualty insurance policies are also generally exempt from reporting to APCDs. These payers are a very small share of total health spending but are important for understanding diagnoses or patient populations that are common under workers' compensation and other types of insurance (e.g., low back pain) and the specialties that treat these groups (e.g., orthopedics and chiropractic care). Medicare and Medicaid data are available through some state APCDs, although access might require a separate application and additional review.

Consequently, APCDs cannot be assumed to be representative of state populations or health care. Enrollees in ERISA plans are the largest missing population: an estimated 105 million Americans out of the 157 million with ESI are covered by self-insured ESI plans, a majority of which are likely ERISA plans. Other excluded payers cover smaller but nontrivial populations. The FEHBP covers 8 million people, the VHA and Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA) cover an estimated 3.2 million people, TRICARE covers 8.5 million people, and an estimated 2.6 million Americans are eligible for care from the IHS. An estimated 28 million Americans were uninsured for all of 2020, and these individuals are also not included in APCDs.[9]

Of the above missing populations, it is important to note that many APCDs continue to receive some data from ERISA plans on a voluntary basis. The other missing populations (federal payers and the uninsured) are not tracked in any state APCDs.

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[9] Coverage estimates are for 2018, 2019, or 2020, depending on the type of coverage. Estimates for self-insured ESI plans are from 2020 (KFF, 2020) and estimates for FEHBP coverage are from 2018 (U.S Government Accountability Office, 2017). Estimates of VHA, CHAMPVA, and TRICARE coverage are from the 2019 Current Population Survey Annual Social and Economic Supplement and the American Community Survey (Keisler-Starkey and Bunch, 2020). Estimates of IHS coverage are from 2015 to 2020 (IHS, 2020), and numbers of the uninsured were estimated using Current Population Survey Annual Social and Economic Supplement and American Community Survey data (Keisler-Starkey and Bunch, 2020).

The exclusion or limited inclusion of specific coverage types might limit the value of APCDs for studying population health, but the importance of any such limitations depends on the population of interest and the question at hand. For some of these missing populations, it might be possible to find similar populations in the APCD (in terms of demographics, socioeconomic status, and the design or generosity of health insurance coverage). Analysis of workers and dependents covered by fully insured ESI can sometimes be informative for observably similar populations covered by ERISA plans. For instance, although an analysis of hospital price variation using the Massachusetts APCD found evidence of within-hospital price differences between fully insured and administrative-services–only plans issued by the same insurers, this effect was small in magnitude compared with the amount of variation documented across hospitals (Craig, Ericson, and Starc, 2021).

In contrast, other populations that are missing from APCDs, including those eligible for care from the VHA and IHS, seem less likely to have any credible analog in the APCD-covered population. Above all, it is unclear how APCDs in their current form could be used to study the uninsured, a population of significant policy interest that faces a fundamentally different landscape from the insured in terms of access to care and exposure to medical spending risk. The scope of APCD data submissions or linkages (discussed in the next section) would likely need to be expanded before APCDs could be productively used to study many of these populations.

The omission of uninsured individuals and self-insured commercial beneficiaries biases studies of population-level utilization because those without insurance have different utilization patterns from those of the insured, and those in large employer plans likely differ from those with other types of coverage, such as Medicaid or Medicare. These exclusions can also raise the potential for attrition bias (patients who no longer appear in the data, e.g., because they change sources of coverage and are no longer covered by a payer participating in an APCD) or other forms of sample selectivity in longitudinal studies that use APCD data to track utilization changes across different payers or types of coverage. These challenges are not unique to APCDs. Similar limitations in coverage are inherent in any administrative data source (e.g., HCUP does not cover Department of Veterans Affairs Medical Centers). The imperative for researchers to understand the target population and interpret their findings accordingly applies whenever researchers use administrative data to draw inferences about a wider population.

Completeness of State APCD Data

As part of our desk research, we searched for estimates of the size and coverage sources of the population covered by state APCDs to analyze the size and characteristics of missing populations, including the range of variation in APCD completeness across states. After initial efforts to gather this information were largely unsuccessful, we e-mailed follow-up requests to all states for which we could not locate any estimates. Information obtained through these efforts is summarized in Table 4.1. We discuss other lessons learned after describing these estimates.

Out of 18 currently existing APCDs, we were able to obtain estimates in nine states of the covered population, the number of covered lives, *or* the percentage of the state population captured in the APCD. In this context, *persons* refers to unique individuals, i.e., after linking individuals with multiple enrollment records at a point in time and de-duplicating so that each individual is counted only once. It is conceptually appropriate to compare this measure with estimates of the total state population or the population in a state that has insurance coverage.

Covered lives refers to the number of members or enrollment records reported by insurance companies and other payers, *without* de-duplicating individuals with multiple coverage records. As Table 4.1 shows, the number of covered lives exceeds the state population in several states, sometimes by a large margin. We report covered lives in Table 4.1 because counts of covered lives were much more readily available from the states than were de-duplicated counts of individuals with enrollment records. Finally, several states, including one that was unable to provide an estimate of the number of unique people, reported a proportion of the state population captured in the APCD. To allow cross-state comparisons, we used 2019 estimates of the state population and the number of people with health insurance produced by the U.S. Census Bureau using the 2019 American Community Survey (ACS) to report APCD coverage as a proportion of the relevant state population.

The key finding from Table 4.1 is that, among nine states that were able to report the number of unique people, an average of 72 percent of the total state population and about 77 percent of the insured population were captured in the APCD. Coverage varies widely across these six states, however, from a minimum of 34 percent to a maximum of 86 percent when compared with the entire state population, or from a minimum of 37 percent to a maximum of 92 percent when compared with the insured state population.

Table 4.1. Persons and Covered Lives Reported to State APCDs in Comparison with State Population

Statistic	(1) Persons in APCD Relative to 2019 State Population (civilian, noninstitutionalized)	(2) Persons in APCD Relative to 2019 Insured Population (civilian, noninstitutionalized)	(3) Covered Lives in APCD Relative to 2019 State Population (civilian, noninstitutionalized)	(4) Covered Lives in APCD Relative to 2019 Insured Population (civilian, noninstitutionalized)	(5) Percentage of State Population in APCD Reported by APCD
Mean	72%	77%	101%	109%	72%
Median	76%	81%	88%	94%	70%
Minimum	34%	37%	74%	79%	59%
Maximum	86%	92%	146%	162%	81%
N	9	9	6	6	5

SOURCE: Population estimates used in columns 1, 2, 3, and 4 are from U.S. Census Bureau, 2019.

NOTES: *N* = Number of states contributing data. This table summarizes a comparison between the number of persons or covered lives reported by state APCDs and the number of people in the state's civilian, noninstitutionalized population as of 2019. Columns 1 and 3 compare the number of unique persons and the number of covered lives in the APCD, respectively, with the entire state population, including the uninsured. Columns 2 and 4 compare the number of unique persons and the number of covered lives in the APCD, respectively, with the number of state residents with insurance coverage, excluding the uninsured. Column 5 summarizes state-reported estimates of the percentage of the state population captured in the APCD from states that reported such a figure directly. APCD-covered population, covered lives, or percentage of state population were reported for 2021 in one state, for 2020 in five states, for 2019 in one state, for 2017 in one state, and for 2011 in one state. 2019 was the most recent year for which ACS health insurance coverage tables were available at the time this report was prepared.

A second finding is that the number of covered lives substantially exceeds the number of unique individuals, and it sometimes exceeds the entire state population by a sizable margin. This is unsurprising; there are many circumstances in which an individual might be reported to the APCD by multiple payers. Examples include Medicare-Medicaid dual-eligibles, commercially insured individuals with pharmacy coverage provided by a Pharmacy Benefit Manager separate from the health insurer that provides their medical coverage, and Medicare fee-for-service enrollees with prescription drug (Part D) coverage.

We would not expect to find that 100 percent of the insured population as reported in the ACS coverage data also appeared in an APCD because the ACS estimates include some civilian noninstitutionalized populations with coverage sources that are excluded from most APCDs, including those covered by ERISA plans, as well as military retirees and dependents of active-duty service members (who might be covered by TRICARE); veterans and dependents or survivors of certain veterans (who might receive care from the VHA or CHAMPVA); federally recognized American Indians and Alaska Natives (who might receive care from the IHS); and federal employees (who might be covered by the FEHBP).

When we reviewed APCDs in early 2021, we found estimates of post-*Gobeille* self-funded plan reporting for only five APCDs. Each state calculates these numbers differently, so comparisons should be interpreted with caution. Three states (Colorado, Maryland, and Massachusetts) reported that around 75 percent of all self-insured enrollees—including enrollees in non-ERISA self-insured plans—were missing from the APCD.[10] A new study from Oregon estimated that 39 percent of self-insured enrollees had their self-insured coverage reported to the APCD (Oregon Health Authority, Office of Health Analytics, 2021).[11] Finally, Rhode Island reported that the number of enrollment records from ERISA plans dropped by 53 percent between 2015 (pre-*Gobeille*) and 2016 (post-*Gobeille*) (Rhode Island Department of Health, 2022).

Apart from the estimates reported in Table 4.1, we learned some additional lessons in our attempts to gather data on the number of unique individuals or covered lives. Although several states were able to share with us routinely produced reports containing aggregate statistics on the number of covered lives or unique individuals, many states were not producing these data as part of their routine processes. In these cases, states responded to our requests by preparing a tabulation of the number of covered lives in the APCD. However, states that reported the number of covered lives sometimes did not distinguish (or document clearly) whether the number of covered lives included medical coverage, pharmacy coverage, dental coverage, or all three. Even with clarity on which enrollment records were included in a covered lives calculation, the ratio of

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[10] Estimates from Colorado are from CIVHC, undated-c; estimates from Maryland are from Maryland Health Care Commission, 2022; and estimates from Massachusetts are from Hobbs and Medinus, 2020.

[11] Oregon also estimated that a higher proportion (61 percent) of individuals with self-insured coverage might appear in the APCD after accounting for self-insured enrollees with secondary coverage from a payer that submits data to the APCD.

unique individuals to covered lives could vary widely across sources of coverage and across states where the prevalence of different coverage sources varies. For instance, it might be common for Medicare fee-for-service beneficiaries to have three or four coverage records (Part A, Part B, Supplemental Medical Insurance [Medigap], and Part D).

In short, many APCDs appear to cover the majority of their state populations, but coverage is far from complete in the states that provided data, and the extent of coverage varies widely across states. Many states, meanwhile, might not routinely report the number of unique individuals appearing in the APCD. Counts of covered lives are more widespread but are very challenging to interpret in terms comparable with external estimates of states' insured populations.

Missing Variables

APCDs are subject to the inherent limitations of health care claims data. Chart review or electronic medical records often capture important patient information that is not relevant to the claims and payment process, particularly direct measurements of health status, such as cancer staging, blood pressure, and lab test results. Some states provide for submission of information that goes beyond what is typically included in claims. For instance, Arkansas collects Logical Observation Identifiers Names and Codes (LOINC) that are designed to capture detail on lab tests and results that are not present in claims data.

There are also limitations in the use of claims data to study prescription drug costs. Because of the widespread practice of manufacturer rebates, which are not reflected in claims data, payments to pharmacies by insurers and Pharmacy Benefit Managers do not capture the net cost to payers of prescription drugs. Similarly, because coupons provided to patients are not captured in claims data, patient liability amounts reported to APCDs could overstate the out-of-pocket cost paid by consumers. Hence, estimates of prescription drug spending and out-of-pocket costs derived from APCD data will need to be interpreted carefully. Again, it is important that users of APCDs understand the inherent limitations of research conducted on claims data and portray their findings accordingly.

Linkages to Other Data Sets

Data linkage between APCDs and other state or federal administrative data sets is a potentially important strategy for APCDs to remedy some of the missing population and missing variable problems discussed earlier. Furthermore, these additional data might allow richer analysis and open up new use cases.

As examples of missing populations, linkage to hospital admission or discharge databases could provide clear evidence on how much hospital utilization is unobserved in the APCD because of incomplete coverage of payers and exclusion of the uninsured. Although we are not aware of any data sources or registries identifying uninsured individuals, linkage of APCD data to patient records from federally qualified health centers, other safety net providers, or health access programs (e.g., Healthy San Francisco) that provide care to the uninsured could also enable APCDs and researchers to study how transitions in and out of uninsurance affect utilization and costs. Because uninsurance is often a transitory state, linkage of APCDs to records of care received by the uninsured (e.g., hospital discharge data or patient records from safety net systems) could be an important new frontier for research and policy analysis on the uninsured.

As an example of missing variables, electronic health records often contain important clinical information (such as test results or biometric measurements) that is not captured in claims data, while cancer registries include comprehensive information about cancer staging and primary cancer sites that cannot always be reliably inferred from claims data. Linkages also could open the door to studying the effects of medical care that might not be reported as insurance claims. For example, linkage between APCD data and COVID-19 vaccination registries could facilitate observational research on the health and cost implications of vaccination. Race and ethnicity information (which we discuss further in the following sections) also might be more complete (or more consistently reported across payers) in such external data sets as cancer registries or death certificates than in claims data. Looking further afield, nonhealth data sets, such as criminal justice records, tax data, or records of participation in public programs, could be invaluable for studying both the social determinants of health and the socioeconomic consequences of health conditions and the health care system. Although some administrative data sets (such as hospital discharge abstracts) can be anonymized in ways that preclude patient-level linkage, facility- or provider-level linkage could be sufficient for validation of APCD data or research on health care markets.

Table 4.2 reports summary findings about existing linkages between APCDs and various non-APCD data sets. In the table, we report whether a data set has ever been linked to an APCD. We also report whether each linkage is reported to be routine or ongoing or if it was a one-time linkage that might not be regularly updated. Although other states might be working on these linkages or have merged data in the past, evidence of these linkages was not readily apparent on their websites.

Table 4.2. Linkages Between APCDs and Other Administrative Databases

Has the APCD Ever Been Linked to . . .	Number of States Ever Linked	Number of States Routinely Linked
Electronic health record (EHR) data?	2	0
State cancer registry?	2	1
State hospital admission or discharge database?	1	0
Birth certificates or other birth records?	2	1
Death certificates or other death records?	3	1
Workers' compensation claims?	1	1
Safety net program (e.g., SNAP, TANF) participation?	0	0
Federal disability insurance (e.g., SSI/SSDI) participation?	0	0
State disability insurance participation?	0	0
Employment, earnings, or tax data?	0	0
Criminal justice records?	0	0
Medical marijuana cards?	1	1
State PDMP?	1	0

NOTES: This table counts how many states (out of 16 states with currently existing APCDs and one state in implementation) clearly answered the question listed on their website so that answers were readily available through our desk research efforts. Two states with existing APCDs (Kansas and New York) were excluded from the analysis because of a lack of publicly available information. We list the number of states for which we could confirm the APCD's policy for each characteristic; thus, each represents a lower bound. PDMP = Prescription Drug Monitoring Program. SNAP = Supplemental Nutrition Assistance Program. SSI = Supplemental Security Income. SSDI = Social Security Disability Insurance. TANF = Temporary Assistance for Needy Families.

In general, Table 4.2 shows that linkages of APCD data to both health and nonhealth external data sets appears to be fairly uncommon. Birth and death records, electronic health records, and cancer registries are each linked to APCD data in at least two states. Among other linkages that we looked for, a linkage was reported in one state for a state Prescription Drug Monitoring Program, a hospital admission or discharge database, workers' compensation claims, and medical marijuana cards. Among the linkages that were reported, routine updates were reported in at most one state for each linkage type. We caution that, as with the summary tables reported in Chapter 3, our desk research strategy likely represents a lower bound on the actual number of states conducting each type of linkage.

Data Quality

Another challenge to working with APCD data can be a lack of consistency in data quality within and across submitters, which can affect the usability of data. APCDs generally apply a uniform set of data quality checks to all data submitters. Within an APCD, data quality tends to improve over time as the data are used more. States also share data quality thresholds and benchmarks through the Data Quality Forum operated by the NAHDO. Nonetheless, submitters might have very different information systems or technical capabilities, and it is likely that different submitters make different errors or omissions. For instance, text fields collected by APCDs often contain codes that are not recognized by the state and that might not be interpretable by data users.

A rule of thumb is that data that are central to a submitter's business (such as diagnoses and charges) tend to be of higher quality than data that have more-limited business use (such as language preference). The HCUP data undergo multiple levels of data cleaning (by both state agencies and HCUP) and harmonization (by HCUP) before distribution to outside researchers. Because there is no analogous multistate research database based on APCDs, comparable cross-state analytic harmonization is not occurring, and there might be fewer groups conducting data quality checks.[12] Working closely with data users can help identify problems with data submissions because users might consider different aspects of the data than considered in the formal data quality checks.

Although each state has different data validation procedures, some states provided more information about these procedures on their websites, and the nature of these validation checks can vary. Table 4.3 reports some summary findings on the results of our data collection.

For example, a validation check might be to confirm that fields are populated and that the field takes on the correct set of values. Although not all states provide information about these validation strategies, we believe that many more are engaging in these types of validation. Other validation checks could examine trends over time; for example, if a payer is suddenly submitting significantly fewer or more records than in previous periods, it could suggest a problem. We also find evidence that many states are engaging in some data cleaning efforts or logical edits to address such issues as data duplication or gaps in data.

Table 4.3. Data Validation

Question About APCD	Number of States Answering Yes
Are there penalties for nonreporting?	9
Has the state done validation or benchmarking exercises?	8
Are any data cleaning, logical edits, or harmonization applied to the enrollment files?	7

NOTES: This table counts how many states (out of 16 states with currently existing APCDs and one state in implementation) clearly answered the question listed on their website so that answers were readily available through our desk research efforts. Two states with existing APCDs (Kansas and New York) were excluded from the analysis because of a lack of publicly available information. We list the number of states for which we could confirm the APCD's policy for each characteristic; thus, each represents a lower bound.

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[12] A stakeholder suggested that participation in HCUP by state hospitalization databases has improved data quality and standardization, but that no parallel nationwide effort exists for APCDs.

Study of Disparities

Given the rich information and large populations contained in APCDs, APCDs would ideally be an important resource for studying geographic or racial/ethnic disparities in health insurance, utilization, and health outcomes. Address information is reliably populated, and APCDs have been widely used to study geographic disparities or produce granular (e.g., ZIP code– or county-level) substate analyses (see Appendix A). However, race and ethnicity data, which do not have a clear business use for most submitters, are not reliably reported to APCDs because they are frequently not captured in claims submitted by providers. (Such information is not required to adjudicate a claim or otherwise determine the amount of payment.) NAHDO examined the completeness of race and ethnicity data for five APCDs using data from 2017 and found that the proportion of records with usable data reported was 28 percent for race (range: 13 percent to 44 percent) and just 12 percent for ethnicity (range: 0 percent to 35 percent) (NAHDO, 2019). Current reports on race/ethnicity data quality from the Colorado APCD do not suggest much improvement as of 2021 (CIVHC, 2021).

We sought to collect data on the demographic composition of APCD-covered populations, including information about age, gender, race, and ethnicity. We found or received some information about demographics for seven out of 18 states with currently existing APCDs. Two states provided information about the age distribution of enrollment records in the APCD, three provided the gender distribution of enrollment records in the APCD, and three provided information about the completeness of race and ethnicity data.

These efforts did not yield enough data to allow informative analyses on whether APCDs captured demographic data that were representative of their state populations. Among states that provided figures to us, age and gender were reported on most enrollment records, but race and ethnicity were frequently missing (as previously indicated by NAHDO). Figures reported by the three states that provided us with breakdowns of race/ethnicity data completeness by payer or by source of coverage suggested that the availability of race/ethnicity data varies systematically across types of payers and across individual commercial payers. One state reported that race data were missing for 82 percent of commercial enrollees and 59 percent of Medicare Advantage enrollees but for only 10 percent of Medicaid enrollees; Hispanic ethnicity data in this state were missing for 79 percent of commercial enrollees and 50 percent of Medicare Advantage enrollees but for zero percent of Medicaid enrollees. Another state reported that race data were missing for 73 percent of commercial enrollees, for only 3 percent of Medicare enrollees, and for less than 1 percent of Medicaid enrollees; Hispanic ethnicity data in this state were missing for 78 percent of commercial enrollees and for zero percent of Medicaid enrollees. The third state that provided information about race and ethnicity data gave counts of records with race and ethnicity variables reported by payer. Of 20 payers reported by that state, nine had no records with race reported and ten had zero records with ethnicity reported. These findings mirror the results of the NAHDO analysis from 2017.

Medicare researchers, facing similar data quality challenges, have developed imputation methods that allow unbiased estimation of group-specific outcomes and racial disparities in administrative data. The Bayesian Improved Surname Geocoding (BISG) algorithm developed at RAND is now routinely used to analyze disparities in Medicare and has been applied to administrative databases missing race/ethnicity data in many other settings (Elliott et al., 2009). This algorithm requires, at a minimum, the patient's last name and census block group (or street address), which are data that are included in the CDL and many—but not all—state APCDs. Data layouts that avoid collecting name and street address thus might inadvertently preclude the use of APCD data to study racial/ethnic disparities in health and health care.

Provider Relationships

Provider market structure, including the horizontal and vertical integration of providers, has been an area of major policy concern in recent years. Studying market structure requires information about provider relationships (such as ownership or health system affiliation) that typically is not directly reported in claims data. Although some of this information can sometimes be imputed from claims data, it can be difficult to do so. Other types of provider relationships, such as accountable care organization participation, might not be observed in claims data either.

Cross-State Comparisons

Making comparisons across states is an important method for assessing state policies. Significant differences in the implementation of APCDs across states can make comparisons across states challenging: If different states establish different submission guidelines, have different requirements about who must report, use different data structures, or use different strategies to create unique identifiers, it can hinder researchers' ability to make direct comparisons across states (Fiedler and Linke Young, 2020). Such organizations as the APCD Council and the SAPCDAC can work to encourage standardization and common approaches to data collection across states; until that happens, direct comparisons will be difficult. Studies comparing within-state changes over time might be more credible (Gordon et al., 2019a), although the validity of these comparisons still rests on assumptions about data quality that are difficult to verify. That said, some research efforts have made progress toward using APCD data for cross-state comparisons (de Jesus Diaz-Perez et al., 2019). One example is the Network for Regional Healthcare Improvement's Total Cost of Care Initiative, which involved the production of standardized claims data from five states to benchmark the costs associated with care in different settings (Network for Regional Healthcare Improvement, undated).

5. Conclusions

APCDs have been used to evaluate and shape policy, to improve our understanding of population health, to reduce costs, and to improve the quality of health care. In this report, we provide background information about the history and current status of state APCD efforts, challenges and limitations that currently exist with implementing and using APCDs, and potential approaches to address certain challenges and limitations. We also provided basic descriptive information about features of state APCDs.

APCDs are an extremely versatile resource for state governments and the public with the potential to serve a wide variety of purposes. In reviewing authorizing state legislation that created state APCDs, we found that the goals of APCDs as articulated by state legislatures encompass a wide variety of objectives. In creating APCDs, the goals most commonly cited by state legislatures were to promote price transparency and facilitate reporting of utilization, spending, and quality data. However, other commonly mentioned goals included measuring quality of care, improving population health, and reducing or controlling the growth in costs of health care; these goals correspond to the widely acknowledged "Triple Aim" of health care reform. When we searched for examples of how APCDs have been used, we found a variety of use cases that show how APCDs have already contributed to these goals. A review of the research literature on APCDs showed that academic research using APCD data has played an important role in advancing some of the goals set out for APCDs—especially understanding population health and evaluating the impacts of policy and reforms. Furthermore, APCDs have contributed to the policy and research discussion of particularly pressing issues, such as rising health care costs, opioid use, prescription drug pricing, and the COVID-19 pandemic.

Notwithstanding the contributions to policymaking, knowledge, and population health that have already been made possible with state APCDs, APCDs have notable limitations that have prevented their full value to society from being realized. The uninsured are an especially vulnerable population and a focus of concern for health policymakers, so the inherent difficulty of studying the uninsured using data on insurance claims and enrollment is an especially notable limitation of APCDs as they currently exist.

However, APCDs have also been hampered by incomplete coverage of some large populations of people with health insurance. As part of our environmental scan, we attempted to collect estimates of the populations that are missing from state APCDs. However, descriptive statistics reflecting the number of unique individuals captured in APCDs and the completeness or representativeness of APCD enrollment data were not readily available in many states, either through the APCD website or through follow-up queries sent to APCD staff. The production of better and more-comparable information about the completeness and representativeness of state APCDs could help researchers and policymakers interpret the findings of analyses using APCD data and might facilitate adoption of APCD data by researchers. Many APCDs appear to cover the majority of their state populations, but coverage is far from complete in the states that provided data, and the extent of coverage varies widely across states. Many states, meanwhile, might not routinely report the number of unique individuals appearing in the APCD. Counts of covered lives are more widespread but are very challenging to interpret in terms that are comparable with external estimates of states' insured populations.

An especially important limitation, which we discussed at length in Chapter 2, is the incompleteness of state APCD data on self-insured ESI plans regulated under ERISA. The U.S. Supreme Court's 2016 decision in *Gobeille v. Liberty Mutual Insurance Company* held that these ERISA plans could not be compelled by state governments to submit data to APCDs.

ESI is the most widespread coverage source in the United States, and the majority of workers with ESI coverage are enrolled in self-insured plans, so the impact of *Gobeille* on the completeness of state APCD data has been substantial. The SAPCDAC, which was convened in 2021 to develop recommendations for a standardized reporting format that might be used for voluntary reporting by group health plans to state APCDs, represents a useful first step in guiding state and federal action that is necessary to address the challenges imposed by *Gobeille*.

The development of a standardized reporting format is potentially important for encouraging voluntary submissions by ERISA plans because a standardized reporting format could reduce the administrative burden that multistate employers and third-party administrators might otherwise face. To provide some background information about the extent of differences across state APCDs, we collected data to describe the basic features of all currently operational mandatory state APCDs. Our environmental scan revealed that the most-notable differences across state APCD formats have to do with file structure, submission methods, collection of direct identifiers, and approaches to creating a longitudinal ID. By design, the CDL represents a data structure and file contents that are similar (but not identical) to a large number of existing state APCDs, and the flat file structure of the CDL and its collection of direct identifiers, including SSNs, reflects the status quo in many states. An important limitation of this study is that our desk research could provide only a lower bound on the number of states adopting any particular feature of an APCD. Although the research team endeavored to find as much information as possible, it is easier to confirm that information is included in an APCD than document that it is not included.

At the time of writing, it has been less than a year since the SAPCDAC's recommendations were published. We think it is too soon to know how the commission's recommendations on a standardized data submission format will ultimately affect the completeness and value of APCD data. Many of the commission's recommendations call for actions to be taken by the states, so implementation will depend on adoption by state decisionmakers. A standardized reporting format might facilitate ERISA plan reporting by reducing burdens on employers and plan administrators with enrollees in multiple states, and a thoughtfully designed standard will be a necessary building block in future federal efforts to further improve the value and comparability of state APCDs.

What we can say, based on our review of the goals and use cases for APCDs, is that many of the SAPCDAC's other recommendations would also promote the goals that were cited by state legislatures as reasons for APCDs to be created in the first place. For example, recommendations that states adopt and maintain privacy protections (Recommendation 7) promote privacy protection. And, as our literature review showed, facilitating data access (Recommendation 8) and promoting research is likely to advance many of the other goals that motivated the creation of state APCDs (such as evaluating health reform, understanding and improving population health, and promoting the Triple Aim).

Although there are challenges and limitations associated with APCDs, a growing number of states are establishing APCDs because they have enormous potential as tools to help shape policy, control costs, and promote population health. State and federal actions to promote the inclusion of ERISA plan data in APCDs will help promote many of the worthy goals set out for APCDs.

Appendix A. Framework for Understanding Use Cases

Because APCDs contain detailed information about health care utilization across a variety of payers, settings, and insurers for many residents in any given state, they have a multitude of potential uses. Table A.1 provides a framework for categorizing use cases and the data requirements for those use cases. In this framework, it is helpful to consider the level of analysis—for example, individual patients or providers. Given a level of analysis, we describe the data requirements and examples of uses.

Table A.1. APCD Use Cases

Level of Analysis	Requirements	Example of Uses
Individual (cross-sectional)	Individual identifier by payer	• Studying a single health care interaction (with no controls for past health) • Measuring process quality of care
Individual (longitudinal)	A unique individual identifier that allows tracking of individuals across payers; these work best when based on name, age, gender, and SSN	• Studying health care utilization over time as individuals transition across different insurance plans or sources of insurance • Studying out-of-pocket spending for individuals with two or more insurance policies at a point in time (e.g., Medicare fee-for-service beneficiaries with Medigap coverage) • Measuring process quality of care for patients with transitions in coverage
Group (employer, union, or multiemployer welfare arrangement)	Unique group identifiers that allow observation of groups within a given insurance plan; these could be particularly valuable if it were possible to identify the industry	• Differences in cost-sharing within an insurance product • Documenting differences in prices paid by different groups • Occupational health surveillance and research
Insurance plans	Identifiers and cost-sharing information for plans within a given insurer	• Impact of different networks offered by a given payer
Insurer	Unique identifiers	• Assessing how utilization and provider payments vary across insurers • Measuring out-of-network billing, e.g., for measuring surprise billing

Level of Analysis	Requirements	Example of Uses
Provider	Provider identifiers that are the same across different insurers	• Provider treatment patterns • Online price comparison tools • Monitoring whether care is provided in low-cost settings when possible • Monitoring network adequacy
Provider organization	Linkage of horizontally or vertically integrated providers	• Impact of horizontal and vertical integration on utilization and outcomes
Local area	Detailed geographic information	• Impact of local area policies or experiences
Disease, diagnosis, and treatment	Diagnosis and treatment	• Study of rare diseases • Treatment patterns outside Medicare-age populations
Population subgroups	Observation of key demographic variables, such as race and ethnicity, or names and addresses that can allow imputation	• Study of racial and ethnic disparities
Population health	Near-complete coverage of population	• Prevalence of disease at the population level

Appendix B. Annotated Bibliography

This annotated bibliography consists of three sections.

The first section, “Research About State APCD Development and Use Cases,” contains reports and perspectives, drawn largely from the gray literature, that discuss the value of APCDs, implementation challenges, or questions about APCD design.

The second section, “Research by States Using APCDs,” highlights eight examples of state-produced reports that used APCD data for public health or policy impact, along with suggestions of additional resources for readers who are interested in seeing additional applications.

The third section, “Academic Research Using APCDs,” presents examples of recent research that illustrates the myriad ways in which researchers are using APCDs. This section primarily includes peer-reviewed journal articles, but gray literature and unpublished working papers are also included. Citations are sorted by year of publication (newest first) and alphabetically within years.

Research About State APCD Development and Use Cases

Bardach, Lin et al., All-Payer Claims Databases Measurement of Care: Systematic Review and Environmental Scan of Current Practices and Evidence, Rockville, Md.: Agency for Healthcare Research and Quality, AHRQ Publication No. 17-0022-2-EF, June 2017. Download
Literature review and environmental scan that maps an approach to creating an inventory of measures of quality, cost, and utilization of care across settings for potential use with an APCD, noting gaps or current barriers to APCD measurement. Gray literature

Fielder, Matthew, and Christen Linke Young, Federal Policy Options to Realize the Potential of APCDs, The Brookings Institution, 2020. Download
Thoughtful analysis with policy recommendations for federal interventions to maximize value of APCDs, including comparison of alternative models for federal involvement in APCDs. Gray literature

National Association of Health Data Organizations, Current and Innovative Practices in Data Quality Assurance and Improvement, 2019. Download
Conference proceedings with extensive discussion of data quality checks/processing methods and other technical details important for APCD design. Gray literature

Gudiksen, Katherine, et al., The Secret of Healthcare Prices: Why Transparency is in the Public Interest, California Healthcare Foundation, 2019. Download

Discussion of health care price confidentiality, including recommendations for confidentiality targeted toward California's ongoing APCD effort. Gray literature

Love, Denise, and Claudia Steiner, Key State Health Care Databases for Improving Health Care Delivery, APCD Council, National Association of Health Data Organizations, New Hampshire Institute for Health Policy and Practice, 2011. Download
Issue brief comparing APCDs to state hospital discharge databases, highlighting strengths and weaknesses of each data source for different use cases and characterizing potential benefits from linking APCDs to hospital discharge databases. Gray literature

Porter, Josephine, Denise Love, Amy Costello, Ashley Peters, and Barbara Rudolph, All-Payer Claims Database Development Manual: Establishing a Foundation for Health Care Transparency and Informed Decision Making, The APCD Council, 2015. Download
Detailed guide to APCD development targeted at state policymakers and APCD administrators. Section 4 ("Technical Build") contains step-by-step guidance on how to specify data submission standards. Gray literature

Releasing APCD Data: How States Balance Privacy and Utility, Freedman HealthCare LLC, 2017. Download
Overview of state APCDs' data release policies and privacy protections. Potentially relevant for illustrating techniques for protecting direct identifiers. Gray literature

Rocco, Philip, Andrew S. Kelly, et al., "The New Politics of US Health Care Prices: Institutional Reconfiguration and the Emergence of All-Payer Claims Databases," *Journal of Health Politics, Policy & Law*, Vol. 42, No. 1, February 2017, pp. 5–52. Download
Discusses politics of state APCD development and factors contributing to APCD focus on price transparency as a central justification for APCD establishment. Peer-reviewed

Key Regulatory Issues Facing APCD States Post *Gobeille v. Liberty Mutual*, APCD Council, National Academy for State Health Policy, National Association of Health Data Organizations, University of New Hampshire, 2016. Download
Background on post-Gobeille options for state APCDs. Gray literature

Brown, Erin, C. Fuse, and Jaime S. King, "The Double-Edged Sword of Health Care Integration: Consolidation and Cost Control," *Indiana Law Journal*, Vol. 92, No. 1, Fall, 2016, pp. 55–112. Download
Discusses APCDs as a strategy for states to control costs and monitor impacts of provider consolidation. APCDs are presented as one of six strategies available for states to respond to provider consolidation. Peer-reviewed

Freedman, John D., Linda Green, et al., "All-Payer Claims Databases—Uses and Expanded Prospects after Gobeille," *New England Journal of Medicine*, Vol. 375, No. 23, 2016, pp. 2215–2217. Download
Discusses impact of Gobeille decision and discusses strategies available to state and federal policymakers for improving APCDs. Peer-reviewed

Research by States Using APCDs

APCD administrators, other state government agencies, and contractors have used APCDs for a wide variety of reports and policy analyses. We drew a small set of examples from the APCD Showcase website maintained by the APCD Council (APCD Showcase, undated). Readers who are interested in examples of other use cases or states should consult the APCD Showcase.

Many states also have online dashboards or other interactive tools that allow consumers, payers, and others to explore APCD data. A recent overview and "report card" of state price comparison dashboards is provided in Murray et al., 2020, available here.

Smoking-Attributable Costs: Medicaid and Private Insurance, Arkansas Center for Health Improvement, 2019. Download
Arkansas applied attributable fraction estimates to private insurance and Medicaid claims in the APCD to measure state and private-sector spending because of smoking, providing employers and state government with estimates that could help quantify the benefits of tobacco-cessation efforts.

Coloradans Accessed Telehealth Services More in March and April 2020 than 2018–2019 Combined, Center for Improving Value in Health Care, 2020. Download
Colorado used the APCD to measure changes in telehealth utilization and payments during the COVID-19 pandemic, producing an interactive report containing estimates for specific diagnoses, service types, payers, and counties within Colorado.

Commercial Case Price Variation Among High-Volume Inpatient Treatments in Minnesota Hospitals (Part 2) July 2014–June 2015, MN All-Payer Claims Database, undated. Download
Minnesota used the APCD to document the level and range of prices for four common, uncomplicated inpatient surgeries, providing employers with information about price variation and low-cost providers that could be used to guide network formation, benefit design choices, or price negotiations.

Impact of the Assignment of Benefits Legislation. Social & Scientific Systems, Inc., 2015. Download

Maryland used the APCD to evaluate whether the state's Assignment of Benefits law succeeded in reducing the financial burden on patients who used out-of-network physician services. Impacts on network participation and costs to private payers were also evaluated, providing policymakers with insights into the law's impacts on multiple stakeholder groups.

Prescription Drugs, Center for Health Information and Analysis, 2021. Download
Massachusetts used the APCD to produce a series of reports comprehensively documenting prescription drug spending by drug class and specific drugs, including an interactive dashboard, allowing payers and policymakers to monitor trends in utilization and spending at a highly granular level.

Report to the New Hampshire Insurance Department: Copayments for Chiropractic Care and Physical Therapy Services, BerryDunn, 2018. Download
New Hampshire used the APCD to conduct a study commissioned by the Insurance Department to evaluate impacts on costs, utilization, and patient access to chiropractic care following implementation of a law capping out-of-pocket prices.

Follow the Money: Pharmaceutical Manufacturer Payments and Opioid Prescribing Patterns in New York State, NYS Health Foundation, 2018. Download
New York used the APCD to test whether payments to physicians from opioid manufacturers were associated with higher rates of opioid prescribing, providing policymakers with information that could help inform regulation of interactions between drugmakers and physicians.

Potentially Preventable Emergency Room Visits, State of Rhode Island Department of Health, 2021. Download
Rhode Island used the APCD to characterize the most-common symptoms associated with emergency department (ED) visits; to identify avoidable ED visits; and to quantify savings to private payers, Medicaid, and Medicare that might result from reducing avoidable ED visits.

Academic Research Using APCDs

As described in the main text, our literature review included literature published between 2016 and May 3, 2021. The full methods are described in the Approach section in Chapter 1. Our literature review showed that the volume of peer-reviewed literature using state APCD data has grown sharply in recent years. The volume of APCD-based research articles dropped in 2020, although this drop seems likely to reflect the impact of the COVID-19 pandemic; the volume of articles published in the first four months of 2021 (January 1 through May 3) already exceeds the number published in 2019. Table B.1 shows the total number of publications found each year. In what follows, we present a summary of key research, providing at most one article from each group of researchers on a given topic.

Table B.1. Published Peer Reviewed Literature Using an APCD, by Year

Year of Publication	Number of Peer-Reviewed Articles Meeting Our Search Criteria
2021 (January 1 through May3)	14
2020	12
2019	26
2018	10
2017	8
2016	8

2021 Articles

Burke, Mary A., Katherine Grace Carman, et al., "Who Gets Medication-Assisted Treatment for Opioid Use Disorder, and Does It Reduce Overdose Risk? Evidence from the Rhode Island All-payer Claims Database," Federal Reserve Bank of Boston Working Papers 21-3, 2021. Download
Illustrates the use of an APCD to study opioid use disorder treatment and barriers to access. Working paper (Rhode Island)

Craig, Stuart V., Keith Marzilli Ericson, et al., "How Important Is Price Variation Between Health Insurers?" *Journal of Health Economics*, Vol. 77, May 1, 2021, p. 102423. Download
Illustrates use of APCD data to measure hospital price variation between hospitals, between payers within hospitals, and within payers between self-funded and fully insured plans. Peer-reviewed (Massachusetts)

DeGuzman, P. B., G. Huang, et al., "Rural Disparities in Early Childhood Well Child Visit Attendance," *Journal of Pediatric Nursing*, Vol. 58, 2021, pp. 76–81. Download
Illustrates use of APCD data to measure geographic (urban-rural) disparities in well-child visits, including timely analysis of COVID-19 pandemic impacts. Peer-reviewed (Virginia)

Desai, Sunita M., Sonali Shambhu, et al., "Online Advertising Increased New Hampshire Residents' Use of Provider Price Tool but Not Use of Lower-Price Providers," *Health Affairs*, Vol. 40, No. 3, March 2021, pp. 521–514. Download
Illustrates use of APCD data to measure hospital price variation between hospitals, between payers within hospitals, and within payers between self-funded and fully insured plans. Peer-reviewed (New Hampshire)

Geissler, K. H., M. I. Cooper, et al., "Association of Follow-Up After an Emergency Department Visit for Mental Illness with Utilization Based Outcomes," *Administration and Policy in Mental Health and Mental Health Services Research*, 2021, p. 11. Download
Illustrates use of APCD to validate whether a widely used process quality measure (follow-up care within 30 days of an ED visit) is associated with improved patient outcomes, and to explore the measure's association with the cost of care. Peer-reviewed (Massachusetts)

Geissler, K. H., B. Lubin, et al., "The Association of Insurance Plan Characteristics with Physician Patient-Sharing Network Structure," *International Journal of Health Economics and Management*, 2021, p. 13. Download
Illustrates use of APCD to study patient referral patterns using social network measures to describe structure of physician patient-sharing networks. Peer-reviewed (Massachusetts)

Hallvik, S. E., N. Dameshghi, et al., "Linkage of Public Health and All Payer Claims Data for Population-Level Opioid Research," *Pharmacoepidemiol Drug Safety*, Apr 29, 2021. Download
Illustrates use of an APCD in combination with other state health data sources to measure opioid use, addressing issues of record linkage across multiple administrative databases. Peer-reviewed (Oregon)

Hawkins, Summer Sherburne, Krisztina Horvath, et al., "Associations Between Insurance-Related Affordable Care Act Policy Changes with HPV Vaccine Completion," *BMC Public Health*, Vol. 21, 2021, pp. 1–9. Download
Illustrates use of multiple APCDs to study impact of ACA regulations and insurance expansions on population health (vaccine completion in young adults). Notable as an example of analysis using pooled data from multiple state APCDs. Peer-reviewed (Massachusetts, Maine, New Hampshire)

Hirsch, E. A., A. E. Barón, et al., "Determinants Associated with Longitudinal Adherence to Annual Lung Cancer Screening: A Retrospective Analysis of Claims Data," *Journal of the American College of Radiology*, 2021. Download
Illustrates use of APCD data to measure adherence to recommended cancer screenings at individual patient level. Peer-reviewed (Colorado)

Kini, V., B. Mosley, et al., "Differences in High- and Low-Value Cardiovascular Testing by Health Insurance Provider," *Journal of the American Heart Association*, Vol. 10, No. 3, 2021, pp. 1–10. Download
Illustrates use of APCD to measure appropriateness of care in context of cardiovascular testing, and to estimate how quality of care occurs across payers. Peer-reviewed (Colorado)

McIntyre, Adrianna L., Mark Shepard, et al., "Can Automatic Retention Improve Health Insurance Market Outcomes?" *National Bureau of Economic Research Working Paper Series* No. 28630, 2021. Download
Illustrates use of APCD to analyze coverage and risk selection impacts of insurance marketplace choice defaults. Working paper (Massachusetts)

Nocka, Kristen, Madeline C. Montgomery, et al., "Primary Care for Transgender Adolescents and Young Adults in Rhode Island: An Analysis of the All Payers Claims Database," *Journal of Adolescent Health*, Vol. 68, No. 3, 2021, pp. 472–479. Download
Illustrates use of APCDs to study preventative care in a small and understudied population (transgender youth and young adults). Peer-reviewed (Rhode Island)

2020 Articles

Benson, N. M., C. Myong, et al., "Psychiatrist Participation in Private Health Insurance Markets: Paucity in the Land of Plenty," *Psychiatric Services*, Vol. 71, No. 12, December 1, 2020, pp. 1232–1238. Download
Illustrates use of an APCD to study participation of mental health providers in insurance. Demonstrates feasibility of linking APCD to physician licensing data to define a universe of providers, including those who do not accept insurance. Peer-reviewed (Massachusetts)

Burke, L. G., X. E. Zhou, et al., "Trends in Opioid Use Disorder and Overdose Among Opioid-Naive Individuals Receiving an Opioid Prescription in Massachusetts from 2011 to 2014," *Addiction*, Vol. 115, No. 3, March 2020, pp. 493–504. Download
Illustrates use of APCD to measure risk of adverse opioid-related outcomes in opioid-naïve patients. Demonstrates linkage of APCD to multiple state databases (including vital statistics and PDMP data) to add outcome variables to analysis. Peer-reviewed (Massachusetts)

Gan, R. W., J. Y. Liu, et al., "The Association Between Wildfire Smoke Exposure and Asthma-Specific Medical Care Utilization in Oregon During the 2013 Wildfire Season," *Journal of Exposure Science and Environmental Epidemiology*, Vol. 30, No. 4, July 2020, pp. 618–628. Download
Illustrates use of APCD for spatial analysis of pollution impacts on health by linking highly granular pollution data to an APCD. Peer-reviewed (Oregon)

Ghili, Soheil, Ben Handel, et al., Optimal Long-Term Health Insurance Contracts: Characterization, Computation, and Welfare Effects, Cowles Foundation for Research in Economics, Yale University, 2020. Download
Illustrates use of APCD to estimate dynamics of health status over the life cycle for use in analyzing optimal duration of health insurance contracts. Gray literature (Utah)

Jonk, Y. C., A. Burgess, et al., “Telehealth Use in a Rural State: A Mixed-Methods Study Using Maine’s All-Payer Claims Database,” *Journal of Rural Health*, 2020, p. 11. Download
Illustrates use of APCD to measure telehealth use, including urban-rural differences and patterns of use across specific services. Peer-reviewed (Maine)

Magel, John, Jaewhan Kim, et al., “Time Between an Emergency Department Visit and Initiation of Physical Therapist Intervention: Health Care Utilization and Costs,” *Physical Therapy*, Vol. 100, No. 10, 2020, pp. 1782–1792. Download
Illustrates use of an APCD to study receipt and timing of follow-up care after an ED visit, and to link receipt of follow-up care to subsequent use of higher-risk or higher-cost interventions, such as back surgery and opioid therapy. Peer-reviewed (Utah)

Myong, Catherine, Peter Hull, et al., “The Impact of Funding for Federally Qualified Health Centers on Utilization and Emergency Department Visits in Massachusetts,” *PLoS ONE*, Vol. 15, No. 12, 2020, pp. 1–14. Download
Illustrates use of APCD to study impact of FQHC funding on FQHC and use of ED visits for emergent versus nonemergent conditions. Peer-reviewed (Massachusetts)

Orfield, N. J., A. Gaddis, et al., “New Long-Term Opioid Prescription-Filling Behavior Arising in the 15 Months After Orthopaedic Surgery,” *Journal of Bone and Joint Surgery-American Volume*, Vol. 102, No. 4, February 2020, pp. 332–339. Download
Illustrates use of APCD data to describe probability of long-term opioid therapy following orthopedic surgery. Peer-reviewed (Virginia)

Panchal, H., M. G. Shamsunder, et al., “Impact of Physician Payments on Microvascular Breast Reconstruction: An All-Payer Claim Database Analysis,” *Plastic and Reconstructive Surgery*, Vol. 145, No. 2, February 2020, pp. 333–339. Download
Illustrates use of APCD to study how patient and payer characteristics, including physician reimbursement policies, affected choice of breast reconstruction method. Peer-reviewed (Massachusetts)

Prager, Elena, and Nicholas Tilipman, “Regulating Out-of-Network Hospital Payments: Disagreement Payoffs, Negotiated Prices, and Access,” Electronic Health Economics Colloquium (EHEC), 2020. Download
Illustrates use of APCD in conjunction with information about insurer network structure to model relationship between out-of-network payments and hospital-insurer bargaining outcomes. Includes analysis of policies that limit out-of-network prices. Working paper (Massachusetts)

Raifman, J., K. Nocka, et al., “Evaluating Statewide HIV Preexposure Prophylaxis Implementation Using All-Payer Claims Data,” *Annals of Epidemiology*, Vol. 44, April 2020, pp. 1–7. Download
Illustrates use of APCD to describe population take-up of HIV PrEP and explore patient and provider characteristics associated with greater take-up. Study includes comparison to estimates from other databases, including pharmacy claims and EMR data. Peer-reviewed (Rhode Island)

Ranade, Ashwini, Gary Young, et al., “Changes in Dental Benefits and Use of Emergency Departments for Nontraumatic Dental Conditions in Massachusetts,” *Public Health Reports*, Vol. 135, No. 5, September 2020, pp. 571–577. Download
Illustrates use of APCD to study impact of Medicaid dental benefit changes on ED utilization for nontraumatic dental conditions. Peer-reviewed (Massachusetts)

Whaley, Christopher, Brian Briscombe, et al., Nationwide Evaluation of Health Care Prices Paid by Private Health Plans: Findings from Round 3 of an Employer-Led Transparency Initiative, Santa Monica, Calif.: RAND Corporation, RR-4394-RWJ, 2020. Download
Large multistate comparison of variation in hospital prices paid by employers and other commercially insured patients; database includes APCD data from six states, illustrating use of APCD data for interstate comparison of hospital prices. Gray literature (Delaware, Colorado, Connecticut, Maine, New Hampshire, and Rhode Island)

Wilson, Thomas, and Janet Sullivan, “Mental/Behavioral Health as a Predictor of Initial COVID-19 Diagnosis: Results from the Colorado All Payer Claims Data Set to June 30, 2020,” Trajectory Healthcare, LLC, 2021. Download
Analysis using Colorado ACPD of mental health diagnoses as predictor of COVID-19 while controlling for other established risk factors. Gray literature (Colorado)

Zhou, Ruohua Annetta, Nancy D. Beaulieu, and David Cutler, “Primary Care Quality and Cost for Privately Insured Patients in and out of US Health Systems: Evidence from Four States,” *Health Services Research*, Vol. 55, 2020, pp. 1098–1106. Download
Illustrates use of multiple APCDs to study impact of health system affiliation on cost and quality for primary care physicians. Study involved linkage of health system affiliation measures to APCDs at the provider level. Peer-reviewed (Colorado, Massachusetts, Oregon, and Utah)

2019 Articles

Brand, E., R. Rodriguez-Monguio, et al., “Gender Differences in Mental Health and Substance Use Disorders and Related Healthcare Services Utilization,” *American Journal on Addictions*, Vol. 28, No. 1, 2019, pp. 9–15. Download
Illustrates use of APCD to study gender disparities in mental health care utilization. Peer-reviewed (Massachusetts)

Brot-Goldberg, Zarek C., and Mathijs de Vaan, Intermediation and Vertical Integration in the Market for Surgeons, Mimeo, University of California, Berkeley. 2019. Download
Illustrates use of APCD to study impact of physician integration on patient referral patterns. Analyzes how changes to market structure and introduction of global budgeting affect costs and patient steering. Working paper (Massachusetts)

de Jesus Diaz-Perez, Maria, Rita Hanover, et al., "Producing Comparable Cost and Quality Results from All-Payer Claims Databases," *American Journal of Managed Care*, Vol. 25, No. 5, 2019, pp. e138–e144. Download
Illustrates methods for comparing cost and quality measures across multiple state APCDs. Introduces the Uniform Data Structure file format for similar cross-state comparisons. Peer-reviewed (Colorado, Massachusetts, Oregon, and Utah)

Garvin, Jennifer Hornung, Kimberly A. Herget, et al., "Linkage Between Utah All Payers Claims Database and Central Cancer Registry," *Health Services Research*, Vol. 54, No. 3, 2019, pp. 707–713. Download
Describes methods for linkage of APCD data to a cancer registry. Peer-reviewed (Utah)

Gordon, Sarah H., Benjamin D. Sommers, et al., "The Impact of Medicaid Expansion on Continuous Enrollment: A Two-State Analysis," *Journal of General Internal Medicine*, Vol. 34, No. 9, September 1, 2019, pp. 1919–1924. Download
Illustrates use of APCD data to study coverage dynamics and continuous coverage in Medicaid, including a comparison across multiple state APCDs to evaluate impacts of ACA Medicaid expansion. Peer-reviewed (Colorado and Utah)

Gordon, S. H., B. D. Sommers, et al., "Risk Factors for Early Disenrollment from Colorado's Affordable Care Act Marketplace," *Medical Care*, Vol. 57, No. 1, 2019, pp. 49–53. Download
Illustrates use of APCD data to study coverage dynamics and predictors of mid-year disenrollment for ACA Marketplace enrollees in Colorado. Includes analysis of coverage sources observed after Marketplace disenrollment and association of individual, county-level, and plan-level factors predictive of early disenrollment. Peer-reviewed (Colorado)

Haakenstad, Annie, Summer Sherburne Hawkins, et al., "Rural-Urban Disparities in Colonoscopies After the Elimination of Patient Cost-Sharing by the Affordable Care Act," *Preventive Medicine*, Vol. 129, 2019. Download
Illustrates use of APCD to study rural-urban disparities in cancer screening and impacts of ACA changes in cost-sharing for preventive services. Peer-reviewed (Maine)

Hashibe, Mia, Judy Y. Ou, et al., “Feasibility of Capturing Cancer Treatment Data in the Utah All-Payer Claims Database,” *JCO Clinical Cancer Informatics*, 2019, pp. 1–10. Download
Illustrates linkage between APCD and cancer registry to capture information about treatment patterns that are not coded in the cancer registry, thereby enhancing the value of the cancer registry. Peer-reviewed (Utah)

Kim, Hyunjee, Christina J. Charlesworth, et al., “Comparing Care for Dual-Eligibles Across Coverage Models: Empirical Evidence from Oregon,” *Medical Care Research & Review*, Vol. 76, No. 5, 2019, pp. 661–677. Download
Illustrates use of APCD to study Medicare-Medicaid dual-eligible population and examines association between different coverage models (including Medicaid fee-for-service and multiple Medicaid Managed Care arrangements). Peer-reviewed (Oregon)

Klevens, R. M., E. Caten, et al., “Outpatient Antibiotic Prescribing in Massachusetts, 2011–2015,” *Open Forum Infectious Diseases*, Vol. 6, No. 5, 2019. Download
Illustrates use of APCD to monitor antibiotic prescribing. Includes analyses of prescribing patterns for specific compounds by specialty and census tract. Peer-reviewed (Massachusetts)

Lavetti, Kurt J., Thomas DeLeire, et al., “How Do Low-Income Enrollees in the Affordable Care Act Marketplaces Respond to Cost-Sharing?” National Bureau of Economic Research, Inc, NBER Working Papers: 26430, 2019. Download
Illustrates use of APCD to study utilization and spending impacts of ACA cost-sharing reductions. Includes linkage to hospital discharge data. Working paper (Utah)

Li, T., S. T. Johnson, et al., “The Impact of High School Athletic Trainer Services on Medical Payments and Utilizations: A Microsimulation Analysis on Medical Claims,” *Injury Epidemiology*, Vol. 6, No. 1, 2019. Download
Illustrates use of APCD to measure health care cost impacts and savings to Medicaid versus commercial payers from provision of high school athletic trainers. Includes linkage of public school enrollment boundaries to patient residence for purposes of assigning exposure to athletic trainers. Peer-reviewed (Oregon)

Lines, L. M., N. C. Li, et al., “Emergency Department and Primary Care Use in Massachusetts 5 Years After Health Reform,” *Medical Care*, Vol. 57, No. 2, 2019, pp. 101–108. Download
Illustrates use of APCD to study utilization of primary care and ED visits for ambulatory sensitive conditions. Includes analysis of utilization differences between public and private payers. Peer-reviewed (Massachusetts)

Menza, Timothy William, and Jeff Capizzi, “1270. Population-Based Estimates of PrEP Access in Oregon, 2012–2016,” *Open Forum Infectious Diseases*, Vol. 6, 2019, pp. S457–S457. Download
Illustrates combination of APCD-based prescription measures with public health surveillance data to quantify unmet need for PrEP among several sexually transmitted disease patient populations in Oregon. Peer-reviewed (Oregon)

Ody, Christopher, and Matt Schmitt, “Who Cares about a Label? The Effect of Pediatric Labeling Changes on Prescription Drug Utilization,” *International Journal of Health Economics and Management*, Vol. 19, No. 3-4, 2019, pp. 419–447. Download
Illustrates use of APCD to study off-label use of pharmaceuticals in children. Includes estimates of impact of drug labeling on market share. Peer-reviewed (New Hampshire)

Panhans, M., “Adverse Selection in ACA Exchange Markets: Evidence from Colorado,” *American Economic Journal: Applied Economics*, Vol. 11, No. 2, 2019, pp. 1–36. Download
Illustrates use of APCD data to study adverse selection in the ACA marketplace, including application of spatial regression-discontinuity methods based on rating area boundaries within a state. Peer-reviewed (Colorado)

Phillips, K. G., A. J. Houtenville, et al., “Using All-Payer Claims Data for Health Surveillance of People with Intellectual and Developmental Disabilities,” *Journal of Intellectual Disability Research*, Vol. 63, No. 4, April 2019, pp. 327–337. Download
Illustrates use of APCD as a health surveillance system to measure the population of people with intellectual and developmental disabilities. Peer-reviewed (New Hampshire)

Rutledge, Regina I., Melissa A. Romaire, et al., “Medicaid Accountable Care Organizations in Four States: Implementation and Early Impacts,” *Milbank Quarterly*, Vol. 97, No. 2, June 2019, pp. 583–619. Download
Illustrates use of APCD data to evaluate impacts of a Medicaid Accountable Care Organization (ACO) in a state (MN) where the state was unable to release claims from Medicaid Managed Care. Peer-reviewed (Minnesota)

Saloner, B., and C. L. Barry, “Changes in Spending and Service Use After a State Autism Insurance Mandate,” *Autism*, Vol. 23, No. 1, 2019, pp. 167–174. Download
Illustrates use of APCD to study utilization and spending impacts of insurance coverage mandate for childhood autism. Uses a single large payer (Kansas State Employee Health Plan) that always covered autism treatment as a control group for commercial payers affected by implementation of a state mandate. Peer-reviewed (Kansas)

Sinaiko, Anna D., Pragya Kakani, et al., "Marketwide Price Transparency Suggests Significant Opportunities for Value-Based Purchasing," *Health Affairs*, Vol. 38, No. 9, September 2019, pp. 1514–1513. Download
Illustrates use of APCD data to describe variation in outpatient prices and model potential statewide savings from price controls or policies to reallocate patients to low-cost providers. Peer-reviewed (Massachusetts)

Steenland, M., A. Sinaiko, et al., "The Effect of the Affordable Care Act on Patient Out-of-Pocket Cost and Use of Preventive Cancer Screenings in Massachusetts," *Preventive Medicine Reports*, Vol. 15, 2019. Download
Illustrates use of APCD to study impact of eliminating cost-sharing for preventive care on use of cancer screenings. Includes analysis of cost impacts and changes in patient cost-sharing associated with implementation. Peer-reviewed (Massachusetts)

Tak, C. R., J. Kim, et al., "Cost-Sharing Requirements for the Herpes Zoster Vaccine in Adults Aged 60+," *Journal of Pharmacy Technology*, Vol. 35, No. 6, 2019, pp. 258–269. Download
Illustrates use of an APCD to measure patient cost-sharing for zoster vaccination for older adults (aged 60–64) nearing Medicare eligibility in comparison with Medicare patients (aged 65+). Peer-reviewed (Utah)

Weber, E., E. Floyd, et al., "Peering Behind the Veil: Trends in Types of Contracts Between Private Health Plans and Hospitals," *Medical Care Research and Review*, 2019, p. 22. Download
Illustrates use of APCD to classify and measure prevalence of different insurer-hospital contract types (fixed rates versus discounted charges versus per diems). Develops algorithm for inferring contract type from claims data and estimates proportion of contracts in each type for Colorado in 2014. Peer-reviewed (Colorado)

2018 Articles

Agha, Leila, Keith Marzilli Ericson, et al., "Team Formation and Performance: Evidence from Healthcare Referral Networks," National Bureau of Economic Research, Inc, NBER Working Papers: 24338, 2018. Download
Illustrates use of APCD to study relationship between physician referral patterns and costs. Working paper (Massachusetts)

Barocas, Joshua A., Laura F. White, et al., "Estimated Prevalence of Opioid Use Disorder in Massachusetts, 2011–2015: A Capture–Recapture Analysis," *American Journal of Public Health*, Vol. 108, No. 12, 2018, pp. 1675–1681. Download
Illustrates use of APCD data in combination with other state administrative databases to estimate prevalence of opioid use disorder using capture-recapture methods. Peer-reviewed (Massachusetts)

Bartels, K., A. Fernandez-Bustamante, et al., “Long-Term Opioid Use After Inpatient Surgery: A Retrospective Cohort Study,” *Drug and Alcohol Dependence*, Vol. 187, June 1, 2018, pp. 61–65. Download
Illustrates use of APCD to describe patterns of postoperative opioid use. Includes analyses of surgery type and past opioid use as predictors of long-term postoperative opioid use. Peer-reviewed (Colorado)

Flaherty, S., K. J. Mortele, et al., “Utilization Trends in Diagnostic Imaging for a Commercially Insured Population: A Study of Massachusetts Residents 2009 to 2013,” *Journal of the American College of Radiology*, Vol. 15, No. 6, June 2018, pp. 834–841. Download
Illustrates use of APCD to describe spending and utilization growth rates over five years for diagnostic imaging in comparison to other procedures. Includes comparison of trends across imaging modalities. Peer-reviewed (Massachusetts)

Ho, Kate, Ariel Pakes, et al., “The Evolution of Health Insurer Costs in Massachusetts, 2010–2012,” *Review of Industrial Organization*, Vol. 53, No. 1, 2018, pp. 117–137. Download
Illustrates use of APCD to study cost growth among commercial insurers over three years. Examines how market dynamics such as consumer plan switching and market entry and exit affect marketwide cost trends. Peer-reviewed (Massachusetts)

Kolstad, Jonathan T., Insurer Innovation and Health Care Efficiency: Evidence from Utah, Working Paper, 2018. Download
Illustrates use of APCD to compare productive efficiency and expenses of commercial insurers, using rigorous methods to adjust for selection of patients across plans and insurers. Gray literature (Utah)

Magel, John, Jaewhan Kim, et al., “Associations Between Physical Therapy Continuity of Care and Health Care Utilization and Costs in Patients with Low Back Pain: A Retrospective Cohort Study,” *Physical Therapy*, Vol. 98, No. 12, 2018, pp. 990–999. Download
Illustrates use of APCD to study association of continuity of care in physical therapy with patient outcomes and costs. Peer-reviewed (Utah)

Malon, Jennifer, Parth Shah, et al., “Characterizing the Demographics of Chronic Pain Patients in the State of Maine Using the Maine All Payer Claims Database,” *BMC Public Health*, Vol. 18, No. 1, 2018. Download
Illustrates use of APCD to measure burden of chronic pain and describe sociodemographic correlates of chronic pain. Peer-reviewed (Maine)

Rossiter, Louis F., “Expenditures and Quality: Hospital- and Health System-Affiliated Versus Independent Physicians in Virginia,” *Southern Medical Journal*, Vol. 111, No. 10, 2018, pp. 597–600. Download
Illustrates use of APCD to study cost and quality impacts of physician market structure and vertical integration. Includes estimates of differences in expenditures and quality between independent physicians and hospital-associated physicians. Peer-reviewed (Virginia)

Whedon, James M., Andrew W. J. Toler, et al., “Association Between Utilization of Chiropractic Services for Treatment of Low-Back Pain and Use of Prescription Opioids,” *Journal of Alternative & Complementary Medicine*, Vol. 24, No. 6, 2018, pp. 552–556. Download
Illustrates use of APCD data to study association of chiropractic care with opioid use. Peer-reviewed (New Hampshire)

Yu, Jiani, Pamela J. Mink, et al., “Population-Level Estimates of Telemedicine Service Provision Using an All-Payer Claims Database,” *Health Affairs*, Vol. 37, No. 12, 2018, pp. 1931–1939. Download
Illustrates use of APCD to describe telehealth use. Includes description of telehealth use patterns across settings, provider types, and payers. Peer-reviewed (Minnesota)

2017 Articles

Barnett, Michael L., Zirui Song, et al., “Insurance Transitions and Changes in Physician and Emergency Department Utilization: An Observational Study,” *Journal of General Internal Medicine*, Vol. 32, No. 10, October 1, 2017, pp. 1146–1155. Download
Illustrates use of APCD to study impact of coverage transitions on physician and ED utilization. Includes analysis of physician switches associated with insurance transitions and comparison of utilization impacts between those entering Medicaid and those entering commercial insurance. Peer-reviewed (Massachusetts)

Figueroa, J. F., A. B. Frakt, et al., “Characteristics and Spending Patterns of High Cost, Non-Elderly Adults in Massachusetts,” *Healthcare-the Journal of Delivery Science and Innovation*, Vol. 5, No. 4, Dec 2017, pp. 165–170. Download
Illustrates use of APCD to describe payer mix and characteristics of patients in the top decile of the spending distribution. Peer-reviewed (Massachusetts)

Finison, Karl, MaryKate Mohlman, et al., “Risk-Adjustment Methods for All-Payer Comparative Performance Reporting in Vermont,” *BMC Health Services Research*, Vol. 17, 2017, pp. 1–13. Download
Illustrates use of APCD to evaluate alternative risk-adjustment methods for application to populations containing a diverse mix of payers, an issue with relevance to multipayer ACOs and similar payment reform models. Peer-reviewed (Vermont)

Hawkins, Summer Sherburne, Alice Noble, et al., “Effect of the Affordable Care Act on Disparities in Breastfeeding: The Case of Maine,” *American Journal of Public Health*, Vol. 107, No. 7, 2017, pp. 1119–1121. Download
Illustrates use of an APCD to study disparities across payers in insurance claims for services and devices to support breastfeeding following implementation of related ACA provisions. Peer-reviewed (Maine)

Kim, Hyunjee, K. John McConnell, et al., “Comparing Emergency Department Use Among Medicaid and Commercial Patients Using All-Payer All-Claims Data,” *Population Health Management*, Vol. 20, No. 4, 2017, pp. 271–277. Download
Illustrates use of APCD to study importance of patient characteristics and local area access to primary care as mechanisms explaining differences between Medicaid and commercially insured populations in ED use. Peer-reviewed (Oregon)

Mafi, J. N., K. Russell, et al., “Low-Cost, High-Volume Health Services Contribute the Most to Unnecessary Health Spending,” *Health Affairs* (Millwood), Vol. 36, No. 10, October 1, 2017, pp. 1701–1704. Download
Illustrates use of APCD to measure volume of spending associated with low-value services. Peer-reviewed (Virginia)

2016 Articles

Charlesworth, C. J., T. H. A. Meath, et al., “Comparison of Low-Value Care in Medicaid vs Commercially Insured Populations,” *JAMA Internal Medicine*, Vol. 176, No. 7, July 2016, pp. 998–1004. Download
Compares low-value care in the Medicaid and commercially insured population. Tests whether provision of low-value care is associated with insurance type. Peer-reviewed (Oregon)

Flecker, Robert H., Seth E. O’Neal, et al., “Evaluating Healthcare Claims for Neurocysticercosis by Using All-Payer All-Claims Data, Oregon, 2010–2013,” *Emerging Infectious Diseases*, Vol. 22, No. 12, 2016, pp. 2168–2170. Download
Illustrates use of an APCD to estimate the frequency of a rare infectious condition. Includes comparison of frequency estimates from APCD to estimates based on hospital data alone. Peer-reviewed (Oregon)

Graven, P. F., T. H. A. Meath, et al., “Preventable Acute Care Spending for High-Cost Patients Across Payer Types,” *Journal of Health Care Finance*, Vol. 42, No. 3, 2016. Download
Illustrates use of APCD to study preventable spending among high-cost patients. Includes analysis of differences across payers and dynamics of spending over multiple years. Peer-reviewed (Oregon)

Appendix C. Supplementary Tables

Available APCDs and Data Layouts

Table C.1 provides a description of key features of APCDs that are currently available. An additional Microsoft Excel spreadsheet is available that provides detailed information about data layouts in the CDL, several state APCDs, and several comparison sources of claims data.

Table C.1. State APCDs by Year of Development

State	Name of APCD	First Year of Data Collection	Receives Medicaid Data	Receives Medicare Data	Available to Independent Researchers
Existing mandatory APCDs					
Arkansas	Arkansas All-Payer Claims Database	2013	Yes	Yes	Yes
Colorado	Colorado All Payer Claims Database	2012	Yes	Yes	Yes
Connecticut	Connecticut All Payer Claims Database	2012	Yes	Yes	Yes
Delaware	Delaware Health Care Claims Database	2017	Yes	No	Yes
Florida	Florida Center for Health Information and Transparency	2015	Yes	No	No
Kansas	Data Analytic Interface	2004	Yes	No	No
Maine	Maine Health Care Claims Database	2003	Yes	Yes	Yes
Maryland	Maryland Health Care Commission Medical Care Data Base	1998	Yes	Yes	Yes
Massachusetts	Massachusetts All-Payer Claims Database	2009	Yes	Yes	Yes
Minnesota	Minnesota All Payer Claims Database	2009	Yes	Yes	No
New Hampshire	New Hampshire Comprehensive Health Care Information System	2005	Yes	Yes	Yes
New York	New York All Payer Database	2014	Yes	Yes	Yes
Oregon	Oregon All Payer All Claims Database	2010	Yes	Yes	Yes
Rhode Island	HealthFacts Rhode Island Database	2010	Yes	Yes	Yes
Utah	Utah All-Payer Claims Database	2009	Yes	No	Yes
Vermont	Vermont Healthcare Claims Uniform Reporting and Evaluation System	2007	Yes	Yes	Yes

State	Name of APCD	First Year of Data Collection	Receives Medicaid Data	Receives Medicare Data	Available to Independent Researchers
Virginia	Virginia All Payer Claims Database	2011	Yes	No	Yes
Washington	Washington State All-Payer Claims Database	2017	Yes	No	Yes
Existing voluntary efforts					
California	California Healthcare Performance Information System	2013	No	Yes	No
Michigan	Michigan Multi-Payer Claims Database	2010	Yes	Yes	Unknown
Missouri	Midwest Health Initiative Commercial Claims Database	Unknown	No	No	Unknown
Oklahoma	MyHealth Access Network (maintains system)	Unknown	Yes	Yes	Unknown
South Carolina	Division of Medicaid Policy Research at the University of South Carolina Institute for Families in Society (maintains system)	Unknown	Unknown	Unknown	Unknown
Texas	University of Texas Center for Healthcare Data (maintains system)	Unknown	Unknown	Unknown	Unknown
Washington	Washington All Payer Claims Database	2004	Yes	No	Unknown
Wisconsin	Wisconsin Health Information Organization Health Datamart	2006	Yes	Yes	Unknown
In implementation					
California	Health Care Cost Transparency Database	Unknown	Unknown	Unknown	Unknown
Georgia		Unknown	Unknown	Unknown	Unknown
Hawaii	Hawaii Health Data Center	Unknown	No (but planned)	No (but planned)	Unknown
Indiana		Unknown	Unknown	Unknown	Unknown
New Mexico		Unknown	Unknown	Unknown	Unknown
West Virginia	West Virginia Health Care Authority Database	Unknown	Yes	No	Unknown

SOURCE: APCD Council, individual state APCD.
NOTES: California and Washington have both mandatory and voluntary efforts. States showing strong interest in forming an APCD are Alaska, Idaho, Kentucky, Montana, Nevada, New Jersey, North Carolina, Pennsylvania, Tennessee, and Wyoming. States showing no current APCD activity are Alabama, Arizona, Illinois, Iowa, Louisiana, Mississippi, Nebraska, North Dakota, Ohio, and South Dakota.

Goals of State APCDs as Reported in the News Media

Table C.2 provides a summary of goals of state APCDs as identified in news articles found using a search of Nexis Uni and U.S. Newsstream databases

Table C.2. Goals of State APCDs Discussed in News Media

Article Title (State)	Reporting Utilization, Spending, and Quality	Facilitating Price Trans-parency	Measuring Quality of Care	Improving Population Health	Reducing or Controlling the Growth of Costs	Supporting Health System Reform or Change	Evaluating State Health Reforms	Furthering Research	Ensuring Privacy	Evaluating Disparities
“Transparency Will Help Drive Down Health Care Costs” (Boozman, 2018) (AR)	1	1	0	0	0	0	0	0	0	0
“Arkansas Gets an ‘F’ on Medical Cost Transparency, Moves Made to Correct” (2015) (AR)	0	1	0	0	0	0	0	1	0	0
“California Must Quickly Implement Policies for Tracking and Controlling Health Care Costs and Price Increases" (Melnick, 2020) (CA)	0	1	0	0	1	0	0	0	0	0
“Get the Facts About the Proposed Office of Health Care Affordability at OSHPD” (California Department of Health Care Access and Information, 2021) (CA)	0	0	0	0	1	0	0	0	0	1
“Despite Pandemic, Progress Continued on Health Care, Coverage, and Costs in California” (Vasquez, 2020) (CA)	0	0	0	0	1	0	0	0	0	0
“Colorado Insurance Legislation Both Friend and Foe to Consumers” (Gillentine, 2010) (CO)	0	0	0	0	0	0	0	1	0	0

Article Title (State)	Reporting Utilization, Spending, and Quality	Facilitating Price Trans-parency	Measuring Quality of Care	Improving Population Health	Reducing or Controlling the Growth of Costs	Supporting Health System Reform or Change	Evaluating State Health Reforms	Furthering Research	Ensuring Privacy	Evaluating Disparities
“Harsh New Spotlight on Colorado Health Prices Promises Change” (Booth, 2012) (CO)	0	0	0	0	0	0	0	0	1	0
“Kefalas Bill to Push Medical Cost Database” (Magill, 2010b) (CO)	1	1	0	0	0	0	0	0	0	0
“Politicos Choose Priorities as New Legislative Session Begins Wednesday” (Magill, 2010a) (CO)	0	1	0	0	0	0	0	0	0	0
“Sen. Morse Empowers Patients and Strengthens Colorado’s Health Care System” (2010) (CO)	0	1	0	0	0	0	0	0	0	0
“Building a Health Claims Database” (Delucia, 2013) (CT)	0	0	0	1	1	0	0	0	0	0
“CT Fails Consumers Looking for Health Care Costs” (Olivero, 2013) (CT)	1	1	0	0	0	0	0	0	0	0
“CT Fails Consumers Seeking Info on Physician Quality” (Olivero, 2014) (CT)	1	0	1	0	0	0	0	0	0	0
“Database of Costs Proposal Raises Concerns” (Sturdevant, 2012a) (CT)	0	1	0	1	0	0	0	0	0	0
“Malloy’s Top Cop for CT Insurance” (2012) (CT)	1	0	0	0	0	0	0	0	0	0
“Pushing Patients to Shop by Price” (Sturdevant, 2012b) (CT)	0	0	0	0	0	0	0	0	1	0

Article Title (State)	Reporting Utilization, Spending, and Quality	Facilitating Price Trans-parency	Measuring Quality of Care	Improving Population Health	Reducing or Controlling the Growth of Costs	Supporting Health System Reform or Change	Evaluating State Health Reforms	Furthering Research	Ensuring Privacy	Evaluating Disparities
"State Creating Health Claim Database" (Stuart, 2013) (CT)	0	0	0	1	1	0	1	0	0	0
An Act to Amend Title 16 of the Delaware Code Relating to the Delaware Health Information Network (Delaware State Senate, 2016) (DE)	0	1	0	1	0	1	1	0	0	0
"DHIN Launches Statewide Health Insurance Claims Database" (Schmidt, 2019) (DE)	0	0	1	0	1	1	0	1	0	0
"DeSantis Health Plan Calls for More Patient Choices" (Sexton, 2018) (FL)	0	1	0	0	1	0	0	0	0	0
"Gov. Scott's Florida First Budget to Make Florida 1st in Improving Transparency and Fighting Price Gouging at Hospitals" (2015) (FL)	1	1	1	0	0	0	0	0	0	0
"Gov. Scott's Securing Florida's Future Budget Makes Investments to Increase Protections and Transparency for Patients and Families" (2017) (FL)	1	1	0	0	1	0	0	0	0	0
"Kansas Awarded $3M Under Affordable Care Act" (Stephenson, 2013) (KS)	0	1	0	0	0	0	0	0	0	0

Article Title (State)	Reporting Utilization, Spending, and Quality	Facilitating Price Trans-parency	Measuring Quality of Care	Improving Population Health	Reducing or Controlling the Growth of Costs	Supporting Health System Reform or Change	Evaluating State Health Reforms	Furthering Research	Ensuring Privacy	Evaluating Disparities
“Kansas Health Policy Authority Awards Thomson Reuters Contract for Health Care Data Integration and Analysis Initiative” (Masterson, 2008) (KS)	0	0	1	1	0	0	0	1	0	0
“Knowing Health Care Prices Is Just the Start. Now, Act on Them” (2014) (ME)	0	1	0	0	0	0	0	0	0	0
“Maine Health Data Organization Introduces New Health Care Quality and Cost Comparison Website” (2015) (ME)	1	1	0	0	0	0	0	0	0	0
“Maine Using Healthcare Claims to Build Database of Medical Care Spending” (Huang, 2003b) (ME)	0	0	0	0	1	0	0	0	1	0
“Starting Jan. 1, Mainers Can Ask Their Doctors for a Price List of Common Procedures” (Moretto, 2013) (ME)	1	1	0	0	0	0	0	0	0	0
“State Databank Explores How Sick People Get Help; A New Databank Studies Insurance Claims to Learn What Illnesses Mainers Have and Where They Get Care” (Huang, 2003a) (ME)	1	0	0	0	1	0	0	0	0	0

Article Title (State)	Reporting Utilization, Spending, and Quality	Facilitating Price Trans-parency	Measuring Quality of Care	Improving Population Health	Reducing or Controlling the Growth of Costs	Supporting Health System Reform or Change	Evaluating State Health Reforms	Furthering Research	Ensuring Privacy	Evaluating Disparities
“MHCC Awarded Additional $1.1 Million Grant for Expansion of Claims Database” (2014) (MD)	0	1	0	0	0	0	0	0	0	0
“Plans for Collecting Enrollment, Benefit, and Institutional Claims Data” (2007) (MD)	0	0	1	1	1	0	0	0	0	0
“AG Coakley Releases Second Report Examining Key Drivers of Rising Health Care Costs” (2011) (MA)	0	0	0	0	0	1	0	0	0	0
“Curing High Health Costs” (Schwartz, 2011) (MA)	1	0	0	0	0	0	0	0	0	1
“State Releases Report on Chronic Pain Procedures” (2015) (MN)	1	1	0	0	0	0	0	1	1	0
“Minnesota Is First State to Require Electronic Submission of all Health Transactions” (2007) (MN)	0	0	0	0	1	0	0	0	0	0
“Minnesota’s Battle Over Health Data” (Sundquist, 2009) (MN)	1	1	0	0	0	0	0	0	1	0
“Citizens Panel Studies Health Care Costs” (2005) (NH)	1	1	0	0	0	0	0	0	0	0
“New Hampshire Health Care Cost Website” (2007) (NH)	0	1	0	0	0	0	0	0	0	0
“Commissioner of Health Speaks to Hanys’ Quality Committee” (2012) (NY)	0	0	1	1	0	0	1	0	0	0

Article Title (State)	Reporting Utilization, Spending, and Quality	Facilitating Price Transparency	Measuring Quality of Care	Improving Population Health	Reducing or Controlling the Growth of Costs	Supporting Health System Reform or Change	Evaluating State Health Reforms	Furthering Research	Ensuring Privacy	Evaluating Disparities
“Governor Cuomo and Legislative Leaders Announce Passage of 2014–15 Budget” (New York State Division of the Budget) (NY)	0	0	1	1	0	0	1	0	0	0
“Anatomy of a Health Care Bill” (Loew, 2009b) (OR)	0	0	0	1	1	0	0	0	0	0
“Early Start on Health Reform” (Loew, 2009a) (OR)	0	1	0	0	0	0	0	0	0	0
“Oregon Developing Comprehensive Health System Reform” (Trapp, 2009) (OR)	0	0	0	1	0	0	0	0	0	0
“State Planning Searchable Health Claims Database” (Bannow, 2014) (OR)	1	0	0	0	0	0	0	0	1	0
“3M Awarded Analytics Contract for Rhode Island’s All-Payer Claims Database” (2014) (RI)	1	1	0	0	0	0	0	0	0	0
“Lt. Gov. Roberts Releases Healthy RI Reform Act of 2008” (RI.gov, 2008) (RI)	0	1	1	0	0	0	0	0	0	0
“Major Elements of Healthy Rhode Island Reform Act of 2008 Pass General Assembly” (2008) (RI)	1	1	0	0	0	0	0	0	0	0
“With Healthfacts, a Deep Dive into Costs Of Care; Database to Help Track Trends, Drive Innovation” (Salit, 2016) (RI)	1	0	0	0	0	0	1	1	0	0

Article Title (State)	Reporting Utilization, Spending, and Quality	Facilitating Price Trans-parency	Measuring Quality of Care	Improving Population Health	Reducing or Controlling the Growth of Costs	Supporting Health System Reform or Change	Evaluating State Health Reforms	Furthering Research	Ensuring Privacy	Evaluating Disparities
“UDOH Claims Database Receives Prestigious Nat’l Honor” (2011) (UT)	1	1	0	0	0	0	0	0	0	1
“Utah Department of Health Gets New Tool to Uncover ‘Real’ Health Care Costs” (2008) (UT)	1	1	0	0	1	0	0	0	0	0
“Auditor's Report: Vermont Could Be Doing More to Make Health Care Costs Transparent for Consumers” (True, 2014) (VT)	0	1	1	0	0	0	0	0	0	0
“Agency Updates Consumer Guide to Cost of Procedures” (2014) (VA)	1	1	0	0	0	0	0	0	0	0
“Data Dig: Claims Information Expected to Reveal the Effectiveness of Medical Treatments” (Burke, 2015) (VA)	0	0	0	1	0	1	0	0	0	0
“How Much for That Surgery? It Depends" (Davis, 2013) (VA)	0	1	0	0	0	0	0	0	0	0
“Gov. Inslee Continues Push for Health Care Cost Transparency, Reaches Agreement for 2015 Legislation” (Office of Governor Jay Inslee, 2015) (WA)	1	0	0	1	0	1	0	0	0	0
“Law Establishes Health Care Database on Quality and Cost" (Rosbach, 2015) (WA)	1	1	0	1	0	1	0	0	0	0

Article Title (State)	Reporting Utilization, Spending, and Quality	Facilitating Price Trans-parency	Measuring Quality of Care	Improving Population Health	Reducing or Controlling the Growth of Costs	Supporting Health System Reform or Change	Evaluating State Health Reforms	Furthering Research	Ensuring Privacy	Evaluating Disparities
“Signing Ceremony for All-Payer Claims Database Legislation Marks New Era of Cost and Quality Transparency in Washington State,” (Washington Health Alliance, 2015) (WA)	1	1	1	0	0	0	0	0	0	0

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