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

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Acknowledgements

List of Abbreviations

AHRQ	Agency for Healthcare Research and Quality
APCD	All-Payer Claims Database
ASPE	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
EDI	Electronic Data Interchange
ERISA	Employee Retirement Income Security Act
ESI	Employer-Sponsored Insurance
FEHBP	Federal Employee Health Benefits Program
FSED	Free-Standing Emergency Department
HCUP	Healthcare Cost and Utilization Project
HHS	Department of Health and Human Services
IHS	Indian Health Service
LOINC	Logical Observation Identifiers Names and Codes
MEDPAR	Medicare Provider Analysis and Review
NAHDO	National Association of Health Data Organizations
NCPDP	National Council for Prescription Drug Programs
NPI	National Provider Identifier
PHI	Protected Health Information
SAMHSA	Substance Abuse and Mental Health Services Administration
SAPCDAC	State All Payer Claims Databases Advisory Committee
SSN	Social Security Number
VHA	Veterans Health Administration

1. Introduction

Purpose

In this report, RAND provides the U.S. Department of Health and Human Services' Office of the Assistant Secretary for Planning and Evaluation with background information on All Payer Claims Databases (APCDs) to support its role with the Department of Labor's State All Payer Claims Databases Advisory Committee (SAPCDAC), which will develop recommendations for a standardized reporting format for the voluntary reporting by group health plans to State APCDs as required by the Consolidated Appropriations Act, FY 2021.

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 single state. As their name suggests, multiple payers (health insurers) submit data on claims and enrollment. By including data from public programs (such as Medicare and Medicaid) and private insurers (including both employer-sponsored insurance (ESI) and other nongroup insurance), APCDs as originally conceived have the potential to allow 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 exclusion of many ESI plans, which hinders APCDs' ability to achieve their full potential. APCDs also exclude uninsured individuals.

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 1995. Today, 30 states have mandatory or voluntary APCDs in existence or development (APCD Council).

State APCDs are not the first effort in the United States to combine records of patient encounters or insurance claims capturing a wide range 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 Utilization Project (HCUP), 2021a). Since 1988, the Healthcare Cost and Utilization Project (HCUP), 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 (Healthcare Cost Utilization Project (HCUP), 2021b).

Hospital discharge databases like HCUP's differ from APCDs in several important ways, however: Data are reported from hospitals or other facilities, rather than payers; information on costs reflects charges rather than paid amounts; and non-hospital care and retail pharmacy claims are not observed. Only those individuals who receive care from a hospital or other covered facility are observed, but those who receive care and are uninsured or who pay for care themselves are included in hospital discharge databases. Other types of care (outpatient, pharmaceutical claims, etc.) may be included in other data sources, but they can only be linked if a common individual identifier is available.

Private multi-payer claims databases such as IBM MarketScan or the Health Care Cost Institute's commercial claims dataset resemble APCDs more closely. These proprietary efforts collect enrollment and claims data from private sector insurers (including Medicare Advantage) or self-insured employers, but often lack complete claims-based data from public payers such as Medicaid and Medicare fee-for-service claims. These data may 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 they 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. Few states provide systematic information about the participation of ERISA plans in their APCDs. In some states, the share of lives covered by self-insured plans reported to APCDs may be as low as 25 percent. Most American workers with ESI coverage in 2020 (67 percent nationwide) were enrolled in self-insured plans, although not all self-insured plans are covered by ERISA (Kaiser Family Foundation, 2020). This has created a significant limitation: APCDs can no longer mandate submission of data on a large proportion of the population covered by employer-sponsored insurance.

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[1] According to IBM, MarketScan databases offer some of the largest convenience samples available in proprietary U.S. databases—with over 245 million unique patients since 1995. In the most recent full data year, MarketScan databases contain health care data for more than 41.1 million covered individuals— large enough to allow 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 https://www.ibm.com/downloads/cas/6KNYVVQ2 .

Approach

The material in this report reflects a literature review and an environmental scan. We also conducted a small number of key informant interviews, and we have drawn on our team's experience and expertise as researchers who have worked with or developed a range of administrative health care databases—including multiple state APCDs.

We conducted a literature review of literature published between 2016 and 2021 using key databases that include published literature (such as PubMed, EconLit, and Web of Science) and that include working papers (including those from the Social Science Research Network and National Bureau of Economic Research) and gray literature.[2] We searched for terms such as APCD, all-payer claims data, all payer all claims, as well as the names of each state APCD currently available. In addition, we included literature from the APCD Council[3] and commentaries and reports written by key stakeholders.

The environmental scan focused on the APCD Council website, state APCD websites, and WestLaw. We conducted an interview with the president of the APCD Council as well as drawing on past interviews with APCD stakeholders. We also draw 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.

Key Findings

- Today, 17 states have mandatory APCDs (with statutorily-mandated reporting from covered payers), an additional seven have voluntary APCDs (without a reporting mandate) ,[4] and seven are currently developing APCDs.
- *Gobeille v. Liberty Mutual Insurance Company* has reduced participation by ERISA plans by determining that states cannot mandate claims data reporting for such plans, affecting the representativeness of the commercial insurance market in such databases. In some states, the share of lives covered by self-insured plans reported to APCDs may be as low as 25 percent.
- APCDs have improved price transparency and have been central to the passage and implementation of state-based legislation related to surprise billing, lowering and controlling costs, and ensuring network adequacy. Notably, states (Colorado,

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[2] The full list of databases searched was: Academic Search Complete, Business Source Complete, EconLit, NBER, Policy File Index, PubMed, RePEc, Scopus, Social Sciences Abstracts, SSRN, and Web of Science.

[3] The APCD Council is a learning collaborative convened and coordinated by the Institute for Health Policy and Practice (IHPP) at the University of New Hampshire (UNH) 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 providing technical assistance to states.

[4] Note that California and Washington have both voluntary and mandatory efforts.

Washington, Maine, and Virginia) may use APCDs to identify benchmark prices for use in surprise, out-of-network billing cases.

- States face potential tradeoffs 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 creation of a longitudinal identifier to allow the tracking of patients over time across insurance types.

- The APCD Council's Common Data Layout 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. Their goal was to identify a potential common format that could reduce the burden faced by plans who must submit to multiple states, especially ERISA plans.

- APCDs must balance the needs of a wide variety of stakeholders: policy makers, providers, payers, employers, consumers, and researchers. Expanding the use cases of APCDs can benefit more groups but also potentially 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 to improve data quality.

- While APCDs have great value to policymakers and researchers, there are challenges and limitations primarily related to missing populations, missing variables, data quality, and the ability to make comparisons across states. It is important for users to understand the limitations of APCD data and to characterize their findings accurately.

- While APCDs could be a potential resource for understanding racial and ethnic disparities, race and ethnicity are not always collected by all payers. 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 reported was 28 percent for race and 12 percent for ethnicity.

- 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.

  - A standardized reporting format for APCDs will help to improve the comparability of APCDs across states and reduce the burden associated with data submission. However, states have different intended and legislated use cases, which may lead some states to make modifications to a common data layout.

2. Key Issues and Best Practices

History, Key Features, and Goals of State APCDs

In 1998, Maryland was the first state to begin collecting data to establish an APCD and began publishing data in 2000. Maine's APCD, which was established in 2003, is considered to be the first APCD 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 range of analyses related to health care costs and utilization. Additional states began implementing APCDs in the years that followed.

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. While APCDs capture similar information from payers, there are key differences in the extent that public payers are included with commercial payers, the availability of data for longitudinal linkage across payers, and the availability of data to independent researchers. Figure 1, based on 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. Today, 17 states have mandatory APCDs (with statutorily-mandated reporting from covered payers), an additional seven have voluntary APCDs (without a reporting mandate),[5] and seven are currently developing APCDs.[6] Table C.1 in Appendix C shows additional information about these APCDs, including the year of formation.

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[5] Note that California and Washington have both voluntary and mandatory efforts.

[6] Based on figures from the APCD Council found at https://www.apcdcouncil.org/state/map Accessed May 8, 2021.
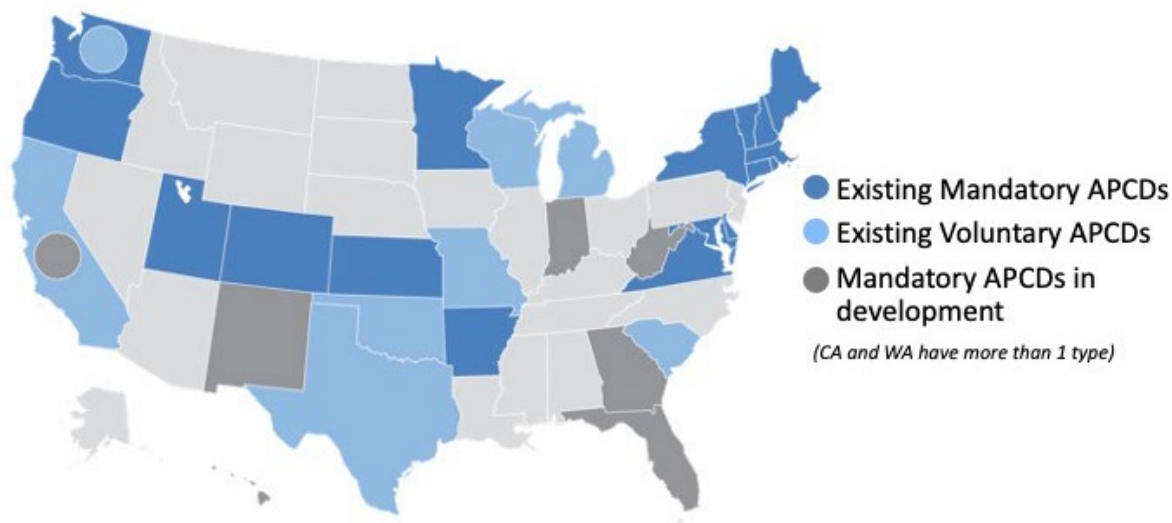
Figure 1: State APCD Implementation as of May 8, 2021

Key Features of State APCDs

Table C.1 in Appendix C provides information about several key features of state APCDs. Key differences across states in the data that their APCDs provide include the inclusion or exclusion of public payers, the ability to link data longitudinally across submitters, and availability to independent researchers. We distinguish between payers and submitters as such: payers represent those organizations that pay for health care, while submitters are only those organizations that are required to submit to the APCD in their state. Some states, such as Maryland, only collect data on private payers and do not include data from state Medicaid programs. In these states, APCDs can only be used to study private coverage without further application to the state Medicaid agency. Often submitters include Medicare Advantage encounters in their submissions; however, 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.

Another important difference relates to how (or if) states create longitudinal identifiers that allow users to follow the same individual over time and across submitters if they change insurance coverage, or to link to other sources of data. Some states (e.g., Colorado, Maine) collect identifying information (direct identifiers) from submitters including name, birthdate, and perhaps Social Security Number (SSN) that can allow for the creation of a longitudinal identifier. Other states, (e.g., Arkansas, Maryland) provide submitters with an encryption key to create a

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unique identifier. While these states do not collect the personally identifiable information, all submitters use the same encryption method and therefore should create the same ID for a given individual. This has the advantage of limiting access to personally identifiable information; however, it also limits states' ability to correct errors in the encryption should they occur, to potentially link to other sources of data, and to use this information directly. As discussed in more detail below, names may also be used to impute unobserved race or ethnicity, which are often not included in APCD submissions.

State legislation and governance policies differ in their treatment of data access and research. Minnesota's APCD is internal to state government and generally restricted to state government use. On the other hand, some APCDs, such as those maintained by Massachusetts, Colorado, New Hampshire, and Utah, are more readily available and have been used widely by researchers. However, the process to acquire access to the data can be a barrier, even among state APCDs that are available to outside researchers. Our experience comparing state APCDs for ASPE revealed wide variability in costs as well as in the complexity and duration of the process for reviewing data requests and releasing data.

Gobeille 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 above, *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. As of 2020, an estimated 67 percent of workers covered by employer-sponsored health insurance were enrolled in self-funded plans (Kaiser Family Foundation, 2020). Not all self-funded plans were affected by *Gobeille*, as 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 completeness of APCD data for the employer-sponsored insurance sector.

In the absence of a federal requirement, state APCDs have had to rely on voluntary data submissions from self-funded ERISA plans. 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 commercial insurance market. In many cases these plans do not submit data to APCDs, limiting their representativeness of the APCD commercial insurance data. Furthermore, the exclusion of large segments of the population make it more difficult to follow individuals over time as they move across insurers and generally make 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 non-submitting ERISA plan. Even when a number of ERISA plans participate, it is possible that participation may 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 easy to imagine, for instance, that an employer cutting costs due to business challenges or changes in management might simultaneously reduce the generosity of coverage and stop submitting APCD data.

The completeness of voluntary reporting by ERISA plans across states is not systematically documented in most states and varies substantially in states where such estimates are available. We found estimates of post-Gobeille self-funded plan reporting for onlyfive APCDs. Note that each state calculates these numbers differently, so comparisons should be interpreted with caution. Three states (Colorado, Maryland, and Massachusetts) report that around 75 percent of all self-insured enrollees—including enrollees in non-ERISA self-insured plans—are missing from the APCD. A new study from Oregon estimated that either 39 percent or 61 percent of self-insured enrollees are in the APCD, depending on the estimation method used. Finally, Rhode Island reports that the number of enrollment records from ERISA plans dropped by 53 percent between 2015 (pre-*Gobeille*) and 2016 (post-*Gobeille*).[7] Exclusion of these groups poses a challenge to interpretation of research findings (M. Fielder, 2020). A standardized reporting format may facilitate ERISA plan reporting by reducing burden 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. Whether a standardized reporting format will be sufficient to encourage voluntary submission remains an open question.

Goals of APCDs

Maryland created the first APCD to support narrowly-defined regulatory activities related to costs and efficiency (APCD Council). Maine's APCD, the second APCD to begin operation, had much broader goals. 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 issue reports." More recent APCDs have been motivated by a wide range of goals, (McCarthy, 2020) including:

- Public reporting on utilization, spending, and quality

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[7] Sources for the estimates in this paragraph are:

Colorado: https://www.civhc.org/get-data/whats-in-the-co-apcd/. Accessed May 28, 2021

Maryland: https://mhcc.maryland.gov/mhcc/pages/apcd/apcd_data_release/apcd_data_release_mcdb.aspx. Accessed May 28, 2021

Massachusetts: https://www.nahdo.org/sites/default/files/2020-08/Day%20Four%20Slides/402-70%20Sylvia%20Hobbs%20NAHDO_August2020_HOBBS_MEDINUS.pdf. Accessed May 28, 2021

Oregon: https://www.oregon.gov/oha/HPA/ANALYTICS/APAC%20Page%20Docs/One-pager-SelfInsured-Lives-and-APAC-April2021.pdf. Accessed May 28, 2021

Rhode Island: https://health.ri.gov/publications/userguide/HealthFactsRIDataUserGuide.pdf. Accessed May 28, 2021

- 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.

The full range of use cases is likely impossible to anticipate at the time an APCD is established, so design choices related to specific use cases may tie the hands of policymakers and researchers in the future. Access to ACPD data has unleashed an impressive degree of innovation as evidenced by our Annotated Bibliography, which includes 68 studies using APCD data published in 2016 or later. Many of the use cases with especially high potential for public health or economic impacts—including 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., 2019), or the cost implications of provider market structure (Brot-Goldberg and Vaan, 2019)—often demand more of the data than simpler applications like price benchmarking and require specific design choices up front to support those use cases. Many of these studies would be impossible without inclusion of longitudinal patient identifiers or direct identifiers that enable linkage to outside databases. Additionally, because APCDs do not include all individuals in a state, there are potentially interesting research questions that cannot be currently addressed using APCD data. Extrapolating from APCD data to draw conclusions about population health warrants particular caution. Using APCDs for public health surveillance activities may not be feasible when segments of the insured population are missing, such as individuals covered by ERISA plans, and they do not include people who are uninsured. For example, in the case of the COVID-19 pandemic, ERISA plan enrollees and the uninsured would have likely had different risks of exposure than other populations. Designing a standardized reporting format that facilitates development of a state APCD common data model that can be used to address various types of needs will be an important point of consideration for the SAPCDAC.

How APCD Analyses have Informed Public Policy

Beyond specific research studies that may 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.[8]

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[8] The ACPD showcase (https://apcdshowcase.org) inventories a wide variety of use cases.

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 only on Medicare inpatient claims (Kullgren, Duey and Werner, 2013), which have limited variation and limited relevance to non-Medicare patients or those seeking non-hospital 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 Center for Improving Value in Health Care (CIVHC) (Center for Improving Value in Health Care), New Hampshire's NH HealthCost (New Hampshire Insurance Department), and Maine's CompareMaine (Maine Health Data Organization and Maine Quality Forum).

Research has shown that a small but non-trivial percentage of patients will use price comparison tools for health services when they are available (Sinaiko, Kakani and Rosenthal, 2019; Whaley et al., 2014; Tu and Lauer, 2009). Consumer-facing price transparency may 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 range of services that are not "shoppable" (e.g., emergency care) (Frost and Newman, 2016; Brown, 2019). 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 may also be able to use price transparency tools to negotiate better rates for certain services. Colorado's CIVHC is currently facilitating these practices by providing standard or customized reports available for employers to purchase (Center for Improving Value in Health Care).

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 non-adherence 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, 2019).

Legislation

Analysis of APCDs has also directly informed or been used to enforce legislation seeking to address patient out-of-pocket spending and control overall health care spending.

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 (WA ST 48.49.04) and Maine (ME ST § 4303-E) also passed similar legislation in 2020. Both the Washington and Maine statutes note that arbitrators may request APCD data to establish reasonable payment amounts in order to resolve disputes between insurers and providers over out-of-network bills. Virginia passed similar legislation in 2020 (VA SB 172), specifically focused on out-of-network emergency services. The legislation notes that the Virginia APCD will be used to set benchmark prices for emergency services.

The federal "No Surprises Act," which takes effect in 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 (*No Surprises Act, H. R. 3630, 116th Congress*, 2020). For non-emergent 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. While 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. This law will in most instances supersede the above-mentioned state laws, except when state law is more stringent and, unlike existing state laws, will also include self-insured plans. In states that have an existing law protecting against surprise billing, their price setting mechanism will remain in place.

Legislation Encouraging Use of Less Expensive Care Settings

APCDs influenced a 2019 Colorado statute requiring Free-Standing Emergency Departments (FSEDs) to explicitly disclose to patients that their facilities are only intended to provide care for 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). This statute (CO ST § 25-3-119 (2019)) on required disclosures was motivated in part by an analysis of Colorado APCD data that found that FSEDs were routinely used to provide non-emergency services.

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." Based on 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 (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 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 noted that the commissioner may analyze Minnesota APCD data to make these determinations.

Network Adequacy

The 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, 2020). In 2018, New Hampshire strengthened its network adequacy law and began analyzing APCD data to ensure that beneficiaries had adequate access to a range 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).

Implementation Challenges

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

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 tradeoff between making the data more usable and increasing the potential

harms to patients if a data breach occurs. PHI comprises 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, social security numbers. Many states collect these data from submitters and create a unique identifier in-house. Others have sought to reduce 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.

The accuracy of longitudinal identifiers also involves tradeoffs 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. 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. While the discussion has focused primarily on the 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 range 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 the summer of 2020. Further, 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 only determine where the prices they face fit in the overall distribution of prices. That is, they might find out that their 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 those 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 as well as 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 those specific providers with the highest prices. Similar issues may 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 well communicated 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 report 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 may be shaped by a state's particular primary use cases. Differences include 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 in order to understand precisely what is being paid for. 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 standard for non-fee-for-service payments will be particularly challenging.

When designing and implementing an APCD, the 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 may 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.

Current Data Reporting Formats

A more uniform data structure, if adopted widely by states, would help to reduce submitter burden and address some of the challenges noted above. In discussing ACPD data structures, it is important to distinguish between the structure of the files submitted to APCDs (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 (affected by the data model used by a state in structuring its consolidated database). We note that there is ample room for greater standardization both of payer submissions (the inputs to the APCD) and of 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).

In an effort to help inform and promote greater standardization in state APCD data, the APCD Council developed a Common Data Layout (CDL), which is intended to capture common practices among states in data submission formats and to 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. Their 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. 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 February 2021. The CDL lays the groundwork for potential cross-state interoperability.

Developing the CDL was feasible because, despite differences in state-specific formats, many states already require a similar structure for data submissions from submitters. The supplementary material for this memo contains a spreadsheet comparing the CDL file structure and included data elements for five state APCDs and, for contrast, three prominent non-APCD multi-payer data sources: the MarketScan Commercial Database, the HCUP National Inpatient Sample (NIS), and the database collected for the RAND Hospital Price Transparency Study. Discussion in this section centers on the CDL, as four of the five included states use a very similar structure. We discuss key differences between the CDL and the fifth state—New York— below. At this point, no APCD has switched from their 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 very costly. However, the authorizing legislation for the recently established Virginia APCD instructs the APCD administrator to use the common data layout, 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.*).

There are two dimensions along which states diverge from the CDL more significantly: the format and submission method of the files submitted, and the approach to handling direct identifier for patients and providers. We discuss each of these in turn. Appendix C provides detailed information about the CDL, several states' submissions, and non-APCD databases.

File Structure and Submission Method

If states were to follow the CDL, submitters would provide five flat files: enrollment files, medical claims, pharmacy claims, dental claims, and provider files. Enrollment data and medical and pharmacy claims are collected by all states; not all states collect dental claims.

States differ most in their approach to the provider file, which contains information (e.g., tax ID number, NPI, specialty, license number, street address) on all providers who submitted claims to that APCD submitter. While the processed APCD data available to researchers generally contain a provider file, not all states require submitters to submit a separate provider file. Those that do not (e.g., Maine and New York) generally require that data about providers similar to the contents of the CDL provider file be attached to medical claim records. A provider file for research uses can then be produced from the claims data by the APCD as part of data processing.

Among non-APCD databases, MarketScan uses a similar file structure to the CDL. The hospital databases (NIS and RAND), in contrast, are designed only to study hospital utilization and lack information on enrollment, pharmacy claims, and dental claims.

However, the relatively new New York APCD has taken a very different approach to data submission. Rather than periodically submitting flat files covering all enrollees and claims from a given time 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. X12 and the

National Council for Prescription Drug Programs (NCPDP) developed the EDI standards adopted by New York to capture data similar to CDL, so it is likely that the research files produced in New York will have substantial overlap with existing APCDs in terms of included variables. However, the data submission process is fundamentally different in New York than in better-established APCD states.

Patient and Provider Identification

Patient and provider identifiers are critical for several basic functions of an APCD.

Patient Identification

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 claims to enrollment records and prescription drug claims submitted in the same month. While 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 is not 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 over time. Many uses of APCD data demand variables that allow linkage of individuals across submitters and over time. As discussed in greater detail above, 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.

The second approach noted above 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 based on 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. While 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 practice, even large and sophisticated submitters have failed to do so, which can require resubmission of data.

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Provider Identification

Being able to identify specific providers is critical for analyses designed to compare payment rates across providers or assess the quality of similar types of providers, e.g., 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. While 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 may 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 are only feasible if all submitters use these identifiers. While the problems associated with identifying providers are not unique to APCDs, they must be faced in designing a common data submission guide.

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. In this section we discuss views held by different stakeholder groups (and how they can at times be in opposition) as well as the importance of stakeholder engagement.

Tradeoffs between stakeholder groups

Different use cases may be viewed differently by different stakeholders. Development and operation of an APCD requires a careful balance of tradeoffs 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 may help purchasers, insurers, and third-party administrators to negotiate lower prices or to implement programs that steer patients towards lower-priced providers. At the same time, a concern expressed by some stakeholders and researchers is that price transparency data may have anti-competitive effects, helping providers to negotiate higher prices with payers (Anthem Public Policy Institute, 2018, Allcott et al. 2021). We note that researchers have differing views on the extent of this concern in health care markets (Sanger-Katz, 2019, Glied 2021): 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) may reduce the scope for such conduct.

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 necessary for a longitudinal identifier (whether it is created at the APCD or encrypted by the submitter) increases the burden to the submitter. Further, creating additional files that meet the formatting and data quality requirements of an APCD also 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 may 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 help to facilitate discussion between APCD staff, data contractors, and users. Ultimately this give-and-take has helped to 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 for non-fee-for-service claims data with multiple stakeholders (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, anti-competitive 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.

Challenges and 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 above, 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)), nor do they 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/casualty insurance policies are also excluded. 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, though access may 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 non-trivial 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 26 to 29 million Americans were uninsured in 2019, 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. The exclusion or limited inclusion of specific coverage types may limit the value of APCDs for studying population

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[9] Coverage estimates are for 2018, 2019, or 2020, depending on the type of coverage.

Sources:

Self-insured ESI plans (2020): https://www.kff.org/health-costs/report/2020-employer-health-benefits-survey/

FEHBP (2018): https://www.gao.gov/products/gao-18-52

VHA, CHAMPVA, TRICARE (2019): CPS ASEC estimates, reported in
https://www.census.gov/library/publications/2020/demo/p60-271.html

IHS (2015-2020): https://www.ihs.gov/newsroom/factsheets/ihsprofile/

Uninsured: 26 million estimated using CPS ASEC; 29 million estimated using ACS. Reported in:
https://www.census.gov/library/publications/2020/demo/p60-271.html

health, but the importance of any such limitations depends on the population of interest and the question at hand.

The omission of uninsured individuals and self-insured commercial beneficiaries biases studies of population level utilization, as those without insurance have different utilization patterns than 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 VA 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.

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 in claims. For instance, Arkansas collects Logical Observation Identifiers Names and Codes (LOINC) that are designed to capture detail on lab tests and results not present in claims data.

There are also limitations in the use of claims data to study prescription drug costs. Due to 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 may 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.

Data Quality

Another challenge to working with APCD data can be a lack of consistency in data quality within and across submitters, which can impact 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

may 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 may 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 multi-state research database based on APCDs, comparable cross-state analytic harmonization is not occurring, and there may be fewer groups conducting data quality checks.[10] Working closely with data users can help to identify problems with data submissions, as users may consider different aspects of the data than considered in the formal data quality checks.

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 or county-level) substate analyses (see Appendix A). However, race and ethnicity data, which do not have a clear business use for most submitters (such information is not required to adjudicate a claim or otherwise determine the amount of payment), are not reliably reported to APCDs, as they are frequently not captured in claims submitted by providers. NAHDO examined the completeness of race and ethnicity data for five APCDs in 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). Current reports on race/ethnicity data quality from the CO APCD do not suggest much improvement as of 2021 (Center for Improving Value in Health Care, 2021).

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), data that are included in the CDL and many, but not all, state APCDs. Data layouts that

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

avoid collecting name and street address may thus inadvertently preclude the use of APCD data to study racial/ethnic disparities in health and health care.

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 (de Jesus Diaz-Perez et al., 2019). 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, this can hinder researchers' ability to make direct comparisons across states (M. Fielder, 2020). Organizations like the APCD Council and 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 may be more credible (Gordon et al., 2019), though the validity of these comparisons still rests on assumptions about data quality that are difficult to verify.

3. Conclusions

APCDs show promise and have been used to impact policy, improve our understanding of population health, reduce costs, and improve the provision and quality of health care. In this report, we have provided 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. A significant limitation has been the exclusion of many self-insured employer sponsored plans governed by ERISA, which since the *Gobeille v. Liberty Mutual* case, can no longer be mandated to submit to 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 SSN reflects the status quo in many states. An implication is that major departures of an ERISA plan reporting format, the focus of the SAPCDAC, from the CDL may reduce compatibility with many of the established APCDs, including newer entrants like Virginia that have adopted the CDL.

In its work to propose an ERISA plan reporting format, SAPCDAC will face a number of tradeoffs. Some approaches to protect privacy may undermine the suitability of APCD data for use cases, with substantial impact on public health or equity. Some approaches to maximizing data completeness may do so at the expense of greater submitter burden. Finally, choosing a single nationwide recommended ERISA plan reporting format will entail unavoidable tradeoffs between compatibility with different existing state formats. Because New York has opted to collect EDI transaction-level data rather than flat files, standardized flat file reporting formats that can be used by all other states will not be readily usable by the New York APCD. Whatever format the Department of Labor adopts, work to coordinate data submission formats and research files across states will need to continue in order for more of the immense potential benefits of APCDs to be realized.

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. The table below 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 then 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)
Individual (longitudinal)	A unique individual identifier that allows tracking of individuals across payers; these work best when based on name, age, gender, and social security number	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 FFS beneficiaries with Medigap coverage)
Group (Employer, union, or multi-employer 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
Provider	Provider identifiers that are the same across different insurers	Provider treatment patterns
		Price transparency

Level of Analysis	Requirements	Example of uses
Provider Organization	Linkage of horizontal 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/treatment	Diagnosis and Treatment	Study of rare diseases
		Treatment patterns outside of Medicare age populations
Population Subgroups	Observation of key demographic variables such as race and ethnicity, or names and addresses that can allow for 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, on "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, on "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 interested in seeing additional applications.

The third section, on "Academic Research Using APCDs," presents examples of recent research that illustrates the myriad of 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 are sorted 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. Prepared under Contract No. 2902001200003I, Task Order 5. Rockville, MD: Agency for Healthcare Research and Quality; June 2017. AHRQ Publication No. 17-0022-2-EF. Download
Literature review and environmental scan, which 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. Grey literature

Young, Matthew Fiedler, and Linke Christen, 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

Current and Innovative Practices in Data Quality Assurance and Improvement, National Association of Health Data Organizations, 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, Samuel Chang, 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. From 2016. 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 range of reports and policy analyses. We drew a small set of examples from the APCD Showcase website maintained by the APCD Council. Readers 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.
https://achi.net/wp-content/uploads/2017/05/Smoking_Costs_MCD_COM_FINAL.pdf
AR applied attributable fraction estimates to private insurance and Medicaid claims in the APCD to measure state and private-sector spending due to 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.
https://www.civhc.org/2020/11/03/coloradans-accessed-telehealth-services-more-in-march-and-april-2020-than-2018-2019-combined/
CO 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.
 https://www.health.state.mn.us/data/apcd/docs/pricevariationpt2.pdf
MN 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. https://mhcc.maryland.gov/mhcc/pages/plr/plr/documents/LGSPT_AOB_rpt_20150115.pdf

MD 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. https://www.chiamass.gov/prescription-drugs

MA 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. https://www.nh.gov/insurance/reports/documents/hb1281chiro_pt_copaystudy.pdf

NH 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. https://nyshealthfoundation.org/wp-content/uploads/2018/06/following-the-money-pharmaceutical-payments-opioid-prescribing-june-2018.pdf

NY 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. https://health.ri.gov/data/potentiallypreventableemergencyroomvisits/

RI used the APCD to characterize the most common symptoms associated with 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. 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 pandemic, and the volume of article published in the first four months of 2021 (Jan 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	Count of Peer-Reviewed Articles Meeting Our Search Criteria
2021*	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 use of an APCD (RI) to study opioid use disorder treatment and barriers to access. Working paper

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 (MA)

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 (VA)

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, Mar 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 (NH)

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 (MA)

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 (MA)

Hallvik, S. E., N. Dameshghi, et al., "Linkage of Public Health and All Payer Claims Data for Population-Level Opioid Research," *Pharmacoepidemiol Drug Saf*, 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 (OR)

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 (MA, ME, NH)

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 (CO)

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 (CO)

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 (MA)

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 (RI)

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, Dec 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 (MA)

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, Mar 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 (incl. vital statistics and PDMP data) to add outcome variables to analysis. Peer-reviewed (MA)

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, Jul 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 (OR)

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 (UT)

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 (ME)

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 (UT)

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 vs. non-emergent conditions. Peer-reviewed (MA)

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, Feb 2020, pp. 332-339. Download
Illustrates use of APCD data to describe probability of long-term opioid therapy following orthopedic surgery. Peer-reviewed (VA)

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, Feb 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 (MA)

Prager, Elena, and Nicholas Tilipman, "Regulating Out-of-Network Hospital Payments: Disagreement Payoffs, Negotiated Prices, and Access," Electronic Health Economics Colloquium (EHEC), 2020. [Download](#)
lllustrates 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 (MA)

Raifman, J., K. Nocka, et al., "Evaluating Statewide HIV Preexposure Prophylaxis Implementation Using All-Payer Claims Data," *Annals of Epidemiology*, Vol. 44, Apr 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 (RI)

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, Sep 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 (MA)

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, RAND Corporation RR-4394-RWJ, 2020. [Download](#)
Large multi-state 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 (DE, CO, CT, ME, NH, RI)

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 CO ACPD of mental health diagnoses as predictor of COVID-19 while controlling for other established risk factors. Gray literature

Zhou, Ruohua Annetta, Nancy D. Beaulieu, 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 (CO, MA, OR, UT)

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 (MA)

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 (MA)

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 (CO, MA, OR, UT)

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 (UT)

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 (CO, UT)

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 (CO)

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, pp. N.PAG-N.PAG. [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 (ME)

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 (UT)

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 (OR)

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 (MA)

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 (UT)

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 vs. 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 (OR)

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 (MA)

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 (OR)

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 (NH)

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 (CO)

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, Apr 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 (NH)

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 (MN)

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 (KS)

Sinaiko, Anna D., Pragya Kakani, et al., "Marketwide Price Transparency Suggests Significant Opportunities For Value-Based Purchasing," *Health Affairs*, Vol. 38, No. 9, Sep 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 (MA)

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 (MA)

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 to Medicare patients (aged 65+). Peer-reviewed (UT)

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 vs. discounted charges vs. 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 (CO)

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 (MA)

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 (MA)

Bartels, K., A. Fernandez-Bustamante, et al., "Long-Term Opioid Use After Inpatient Surgery - A Retrospective Cohort Study," *Drug and Alcohol Dependence*, Vol. 187, Jun 1, 2018, pp. 61-65. [Download](#)
Illustrates use of APCD to describe patterns of post-operative opioid use. Includes analyses of surgery type and past opioid use as predictors of long-term post-operative opioid use. Peer-reviewed (CO)

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, Jun 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 (MA)

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/exit affect marketwide cost trends. Peer-reviewed (MA)

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

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 (UT)

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 (ME)

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 (VA)

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 (NH)

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 (MN)

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 (MA)

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 (MA)

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 multi-payer ACOs and similar payment reform models. Peer-reviewed (VT)

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 (ME)

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 (OR)

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, Oct 1, 2017, pp. 1701-1704. [Download](#)
Illustrates use of APCD to measure volume of spending associated with low-value services. Peer-reviewed (VA)

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, Jul 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 (OR)

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
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Appendix C. Available APCDs and Data Layouts

Table C.1 provides a description of key features of APCDs that are currently available. An additional Excel spreadsheet is also available to provide detailed information about data layouts in the CDL, several state APCDs, as well as 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	Yes	Yes
Kansas	Data Analytic Interface (DAI)	2004	Yes	No	No
Maine	Maine Health Care Claims Database	2003	Yes	Yes	Yes
Maryland	Maryland Health Care Commission Medical Care Data Base (MCDB)	1998	No	No	Yes
Massachusetts	Massachusetts All-Payer Claims Database	2009	Yes	Yes	Yes
Minnesota	Minnesota All Payer Claims Database (MN APCD)	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 (APAC) 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 (VHCURES)	2007	Yes	Yes	No
Virginia	Virginia All Payer Claims Database	2011	Yes	No	Yes
Washington	Washington State All-Payer Claims Database (WA-APCD)	2017	Yes	No	Yes
Existing Voluntary Efforts					
California	California Healthcare Performance Information System (CHPI)	2013	No	Yes	No
Michigan	Michigan Multi-Payer Claims Database	2010	Yes	Yes	Unknown
Missouri	Midwest Health Initiative Commercial	Unknown	No	No	Unknown

State	Name of APCD	First Year of Data Collection	Receives Medicaid Data	Receives Medicare Data	Available to Independent Researchers
	Claims Database				
Oklahoma	MyHealth Access Network (maintains system)	Unknown	Yes	Yes	Unknown
South Carolina	Division of Medicaid Policy Research (MPR) 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	WHIO Health Datamart	2006	Yes	Yes	Unknown
In Implementation					
California	Health Care Cost Transparency Database	Unknown	Unknown	Unknown	Unknown
Florida	Florida Agency for Health Care Administration (maintains system)	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

[*] States showing strong interest in forming an APCD: Alaska, Idaho, Kentucky, Montana, Nevada, New Jersey, North Carolina, Pennsylvania, Tennessee, Wyoming. States showing no current APCD activity: Alabama, Arizona, Illinois, Iowa, Louisiana, Mississippi, Nebraska, North Dakota, Ohio, South Dakota
Sources: APCD Council, Individual State APCD
Note: California and Washington have both mandatory and voluntary efforts.

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