### STATE ALL-PAYER CLAIMS DATABASES Tools for Improving Health Care Value

# Part 1: How States Establish an APCD and Make It Functional

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#### ABSTRACT

**ISSUE:** All-payer claims databases (APCDs) can facilitate state efforts to control the rising cost of health care and increase its value. By aggregating data on the health care services that health insurers and public programs pay for, they offer a broader perspective on cost, service utilization, and quality than any single entity can provide. An increasing number of states are creating or are implementing APCDs.

**GOALS:** Synthesize experiences and lessons learned from the creation and implementation of eight diverse, state-level APCDs, including their intended uses, formation, governance, funding, staffing, use of vendors, sources and types of data collected, linkages with other data, analytic capabilities, and privacy practices.

**METHODS:** Interviews with APCD staff and stakeholders and a review of documentary evidence.

**KEY FINDINGS AND CONCLUSIONS:** State approaches to APCD development varied from governmental initiatives and public-private partnerships to voluntary efforts. Successful implementation requires engaging with stakeholders; establishing salient use cases; determining a suitable governance structure; securing sustainable funding; setting realistic implementation goals and timeframes; and ensuring data quality and analytic rigor while protecting data privacy.

#### TOPLINES

- By aggregating data on patient services that insurers and public programs pay for, all-payer claims databases can aid states' efforts to control rising costs and increase the value of health care.
- An effective all-payer claims database requires buy-in from key stakeholders in a state, a suitable governance structure, sustainable funding, realistic implementation timeframes, and adherence to data quality and privacy standards.



#### **INTRODUCTION**

Identifying and addressing the drivers of high health care costs are more important than ever. Growth in health care spending has been a major component of growth in state budgets, which are being strained by a decline in tax revenues during the COVID-19 pandemic.<sup>1</sup> The high cost of health care is also reducing employers' ability to maintain health insurance benefits, especially during an economic downturn, and continues to burden consumers with out-ofpocket expenses that compete with other basic needs.<sup>2</sup>

Controlling health care spending and ensuring its value require having systemwide information on costs, utilization, and quality of services that no single purchaser or payer can produce. To construct a more comprehensive picture of the health care delivered to their residents, 21 states have created or are implementing all-payer claims databases (APCDs) to collect and aggregate information on payment for health services from commercial health insurers, some self-insured employee benefit plans, and the Medicaid and Medicare programs (Exhibit 1).<sup>3</sup> Another 11 states have indicated strong interest in doing the same. In several states, stakeholders such as health care systems, purchasers, and researchers have voluntarily created APCDs.<sup>4</sup>

This report, the first in a two-part series, summarizes the experiences of eight state APCDs. The purpose is to inform states what to consider when creating an APCD, and help states realize the potential of their APCD. Study sites (Exhibit 2) were selected to exemplify diverse approaches and contexts for implementing an APCD as well as the challenges and benefits of doing so (see the section, "How This Study Was Conducted"). The APCDs, which have been in operation for four to 17 years, were also selected to highlight advanced uses of data (as described in the companion report). This series builds on existing research,<sup>5</sup> including a previous case study examining how Massachusetts leverages data generated by its APCD to inform a statewide cost-containment agenda.<sup>6</sup>

In Implementation Strong Interest Existing Voluntary Effort

#### Exhibit 1. State Activity on All-Payer Claims Databases

Existing



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**Study Sites** 

APCD	APCD Administrator	Type of Organization	State Authority*
Arkansas All-Payer Claims Database	Arkansas Center for Health Improvement (ACHI)	Health policy organization affiliated with state academic medical center	Arkansas Insurance Department
Colorado All-Payer	Center for Improving Value in	Multi-stakeholder nonprofit	Colorado Department of Health
Claims Database	Health Care (CIVHC)	organization	Care Policy and Financing
Maine Health Care	Maine Health Data Organization	Independent state agency	MHDO board of directors
Claims Database	(MHDO)		appointed by governor
Minnesota Health	Minnesota Department of	State agency	Minnesota Department of
<b>Care Claims Reporting</b>	Health (MDH), Health Economics		Health
System	Program		
New Hampshire Comprehensive Health Care Information System	New Hampshire Insurance Department (NHID) in partnership with the N.H. Department of Health and Human Sancises (DHHS)	State agency	NHID: Authority for data collection DHHS: Authority for data releases
Utah All-Payer Claims Database	Utah Department of Health (UDOH), Office of Health Care Statistics	State agency	Health Data Committee appointed by governor and reporting to UDOH
Virginia All-Payer Claims Database	Virginia Health Information (VHI)	Multi-stakeholder nonprofit organization	Virginia Department of Health
WHIO Intelligence Bank	Wisconsin Health Information Organization (WHIO)	Multi-stakeholder nonprofit organization	Wisconsin Department of Health Services

#### Exhibit 2. APCD Study Sites and Governance

\*Note: Authority means a statutory or contractual authority to collect, use, and/or release health care claims data. Source: Author's analysis.

#### **CREATING A STATE APCD**

Creating a state APCD involves identifying its intended uses, garnering support for its formation, defining a governance structure, securing funding for its development and operation, employing staff, and (in most cases) contracting with an information technology (IT) vendor.

#### **Intended Uses**

Proponents of state-level APCDs offer a variety of motives for their creation.<sup>7</sup> Some appeal to information transparency in the belief that disclosing and highlighting variation in the utilization, cost, and quality of services will equip employers to purchase care based on its value and stimulate consumers to be more cost-conscious, thereby strengthening markets.<sup>8</sup> Others view an APCD as a tool to enhance the ability of states to oversee insurance markets, public coverage programs, and public health. APCDs are often regarded as a rich source of data for health care research and health system improvement.

Some states have an expansive vision for their APCDs, the goal being to support health system change (Exhibit 3). However, with limited resources it can prove difficult to fulfill many different purposes. Several interviewees recommended that organizers focus on key use cases that will appeal to state policymakers and other primary users by reflecting a clear vision for data-driven decisionmaking. Careful planning is needed to ensure that enabling legislation, technical infrastructure, and potential data sources will support the range of intended uses.<sup>9</sup>

#### Exhibit 3. Strategic Vision for the Colorado APCD



Source: Center for Improving Value in Health Care (CIVHC).

#### Formation

Developing and implementing the studied APCDs required from one to three years. The impetus often came from broader state health care reform initiatives that convinced governors and legislators of the need for comprehensive and objective data on health system performance. Nevertheless, proponents sometimes had to overcome concerns raised by the health care industry, such as the hidden cost of a mandate to submit claims or objections to the disclosure of proprietary information, as well as resistance from dominant market players concerned about the increased competition that might result from publishing health care prices.

The route that states took to establishing an APCD was not always straightforward. It often involved persuasion by influential "champions," political compromises, and an unpredictable iterative process. Virginia, for example, initially allowed insurers to voluntarily submit claims data. Later, to expand the APCD's scope, the state mandated claims submission. In contrast, Minnesota's APCD was first envisioned as a tool to advance transparency. Industry influence and privacy concerns led the state to use the APCD in a more limited way, supporting research and evaluation by the state health department.

#### **Authority and Governance**

Seven of the eight study states, by law, vest oversight authority for their APCDs in state rule-making agencies including insurance and health departments, a Medicaid agency, and an independent state authority (Exhibits 1 and 5). These agencies have the authority to mandate submission of health care claims data by health insurers. The state agencies administer their APCDs in four of these seven states. The other three states contract with independent administrators, which include a universitybased policy institute and nonprofit organizations with multistakeholder boards that include state-appointed officials.<sup>10</sup> In the eighth state, Wisconsin, the APCD is governed by a voluntary organization, made up of private stakeholders and state agencies. This fulfills a statutory requirement for an APCD while relying on contractual and voluntary submission of claims data.

State-authorized APCDs typically have state-appointed advisory committees to promote public accountability, such as by guiding the scope of data collection, ensuring compliance with privacy laws, and reviewing the appropriateness of data releases (see Exhibit 4). Stakeholders on these bodies also serve as an important source of input to help ensure that the administration and uses of the APCD remain responsive to constituent needs.

#### Funding

APCD administrators reported a wide range of annual operating costs that may reflect variation in the scope of their missions and capabilities as well as differences in their budgeting and accounting methods (Exhibit 5). Some state officials contend that a relatively lean operation allows an APCD to achieve its objectives in a nimble and cost-efficient manner. Other leaders say that realizing the full potential of an APCD requires ongoing investment in operational, analytic, and reporting capabilities and expertise. Funding sources include state appropriations, industry contributions, contracts and data use or licensing fees, and government and private grants.

- Appropriations. Most study sites receive core operating funds through state appropriations. Several states get federal help supporting their APCD with a match of the state's Medicaid funding.<sup>11</sup> Virginia and Colorado initially depended on private sources of support and only later obtained a state appropriation after demonstrating the value of the APCD.
- *Industry assessments.* The Maine Health Data Organization (and its APCD) is supported by a statemandated annual assessment on health care providers and health plans based on net patient revenue, premiums written, or a flat dollar amount.<sup>12</sup> Industry stakeholders are major users of APCD data, which means they easily realize the value of this support.
- Contracts and fees. Most study sites charge customers

   enough to recover their costs, at least for custom datasets, nonpublic reports, and data analyses.<sup>13</sup> A few offer subscriptions to the database, to users with the sophistication to make effective use of raw data and protect its security. Some sites offer discounts to nonprofit organizations and/or academic researchers that meet certain criteria.

#### Exhibit 4. Arkansas APCD Governance Structure



#### Healthcare Transparency Initiative Governance Structure

Source: Arkansas Center for Health Improvement.

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• *Grants.* Most of the study states have received federal, state, or private grants to fund the development or enhancement of their APCDs and/or to create analytic capability and reports in support of various time-limited projects of interest to funders.<sup>14</sup>

#### Staffing

The wide variations in APCD staffing (Exhibit 5) may reflect differences in the scope of supported use cases, the number of data submitters and data requests, varying approaches to using vendors and in-house staff for data management, and the extent of data quality assurance and customer relations activities. Several APCD leaders emphasized the need for dedicated staff resources and expertise to ensure the accuracy, consistency, and reliability of data.

#### Information Technology Vendors

Seven of the APCD states contract for data management and/or analytics with external IT vendors (Exhibit 5). Utah relies in part and Arkansas relies entirely on in-house IT. APCD leaders emphasized selecting a vendor that can meet operational goals, being willing to change vendors when necessary, and not becoming overly reliant on vendors.

#### **APCD FEATURES: LOOKING INSIDE THE BOX**

The utility and integrity of an APCD depends on the sources and types of data it collects, the data linkages it supports, the analytic tools it employs, the ways it protects data privacy, and restrictions on the use and disclosure of its data.

#### **Sources of Data**

State APCDs collect claims data from multiple payers (Exhibit 5), which requires building and managing effective working relationships with data submitters. The seven study states that rely on statutory authority for data collection require most commercial health insurers and Medicare Advantage plans doing business in the state to submit claims data on state residents to their APCDs.<sup>15</sup> To manage a quality database, you have to work in tandem with your vendor to provide oversight, quality control, local knowledge, and expertise to define business rules and identify where improvement can and should be made.

Ana English CEO, Colorado's Center for Improving Value in Health Care

Wisconsin relies on contractual and voluntary submission of claims data, which means that its APCD does not always obtain all key data elements from all submitters.<sup>16</sup> All study APCDs also incorporate claims data from their state Medicaid program and the traditional Medicare program.<sup>17</sup>

The U.S. Supreme Court ruled in 2016 that the Employee Retirement Income Security Act (ERISA) exempts private employers' self-insured health plans from state laws requiring claims data submission to APCDs.<sup>18</sup> States can and typically do require data submission from selfinsured public employers not subject to ERISA including cities, counties, schools, and the state's own employee benefit plan (which may include state universities).<sup>19</sup> To encourage voluntary submission of claims by private employers and purchasing coalitions, some states disseminate opt-in forms and educate employer groups on the value of participation. Through such efforts, a few states have been able to maintain data on a sizable share of self-insured lives.<sup>20</sup>

#### **Types of Data Collected**

All study sites collect medical and pharmacy insurance claims data in specified formats as well as eligibility and enrollment data about the individuals covered by the insurance plan (Exhibit 6).<sup>21</sup> Five of the eight study states also collect dental insurance claims data.

#### **Exhibit 5. APCD Characteristics and Features**

STATE	ORGANIZATION			ON CONTEXT						RESO	JRCES		FU	INDI	IG SC	VENDOR							
	Sta	ate		NPO		State C	e Rai Grad	nk o e						St	aff	Buc	lget						
	State Executive Branch Agency	independent state Agency	University Under State Conract	Nonprofit Under State Contract	Health System Performance	Insurance Market Competition	Ensuring Data Is Available for Use	Healthcare Price Transparency	Expanded Medicaid Under ACA	Date APCD Created	Date APCD Operational	Years for APCD Development	Years APCD in Operation	APCD Core Staff (FTEs)	Agency/Organization Staff (FTEs)	APCD Budget (millions)	Agency Budget (millions)	State Appropriation	Federal Medicaid Match	Industry Contributions	Grants	Fees and Contracts	
Arkansas			Х		47	26	17	D	Y	2014	2016	2	4	2.2	10.0	\$1.8	\$7.0	Х	Х		Х	Х	In house
Colorado				Х	9	12	1	В	Y	2010	2012	2	8	12.0	26.6	\$4.2	\$5.3	Х	Х		Х	Х	HSRI/NORC
Maine	>	K			12	17	4	А	Y	2003	2003	1	17	NA	7.0	NA	\$2.0			Х		Х	HSRI/NORC
Minnesota	Х				3	14	10	С	Y	2008	2009	1	11	10.5	25.0	NA	NA	Х			Х		Onpoint
New Hampshire	Х				10	32	37	А	Y	2003	2005	2	15	1.5	NA	\$1.2	NA	Х			Х		Milliman/HSRI
Utah	Х				11	36	11	D	Y	2006	2009	3	11	3.5	6.0	\$0.8	\$1.7	Х	Х		Х	Х	Milliman
Virginia				Х	29	5	14	С	Υ	2012	2013	1	7	2.6	12.0	\$1.4	\$9.0	Х	Х	*	Х	Х	Milliman
Wisconsin				Х	12	1	35	F	Ν	2007	2008	1	12	7.0	7.0	NA	NA					Х	SymphonyCare
COUNT	3 1	1	1	3														6	4	1	6	6	7
AVERAGE					17	18	16	С	Υ	2008	2009	2	11	5.6	13.4	\$1.9	\$5.0						
MEDIAN					12	16	13	С	Y	2008	2009	1.5	11	3.5	10.0	\$1.4	\$5.3						

STATE	AUTHORITY						DATA SOURCES						DATA TYPES								A LII	NKA(	GES	ANALYTICS					
	Ту	ре		Auth	ority								Clai	ms			Oth	ner											
	Statutory Mandate	Voluntary/Contractual	Insurance Department	Health Department	Medicaid Agency	Other	Commercial Insurers	Self-Insured Employers (voluntary)	Medicaid	Medicare Fee-for-Service	Medicare Advantage	Medical Claims	Pharmacy Claims	Dental Claims	Workers Compensation Claims	Alternative Payment Models	Prescription Drug Rebates	Provider or Health Plan Quality	Provider Financial Performance	Hospital Encounters	Vital Records (births/deaths)	Registries (e.g., cancer, immunizations)	Electronic Health Records	Episode or Case-Mix Grouper	Risk Adjustment or Risk Scoring	Geographic Variation	Low-Value Care	Provider Resource Use	Reference-Based Pricing
Arkansas	Х		Х				Х	Х	Х	Х	Х	Х	Х	Х	Х					Х	Х	Х		Х	Х	Х	Х		
Colorado	Х				Х		Х	Х	Х	Х	Х	Х	Х	Х		Х	Х	Х				*	*	Х	Х	Х	Х	Х	Х
Maine	Х					Х	Х	Х	Х	Х	Х	Х	Х	Х				Х	Х	Х	*	*	Х	Х	Х	Х	Х	Х	Х
Minnesota	Х			Х			Х	Х	Х	Х	Х	Х	Х											Х	Х	Х	Х		
New Hampshire	Х		Х				Х	Х	Х	Х	Х	Х	Х	Х				Х						Х	Х	Х			
Utah	Х			Х			Х	Х	Х	Х	Х	Х	Х	Х				Х		Х	Х	Х		Х	Х	Х	*	Х	
Virginia	Х			Х			Х	Х	Х	Х	Х	Х	Х					Х	Х	Х				Х	Х	Х	Х	Х	
Wisconsin		Х				Х	Х	Х	Х	*	Х	Х	Х					Х					*	Х	Х	Х	Х	Х	
COUNT	7	1	2	3	1	2	8	8	8	7	8	8	8	5	1	1	1	6	2	4	2	2	1	8	8	8	6	5	2

Source: Author's analysis. Notes: NA = Not Available; NPO = Nonprofit Organization. Operational Date = the year when the APCD began receiving claims from data submitters. Staffing = APCD reflects approximate portion of full-time equivalent (FTE) agency or organizational staff time devoted to core APCD operational duties (not counting vendor staffing). APCD Budget = the portion of agency or organizational funding dedicated to core APCD operations; states may not be strictly comparable due to differences in budgeting and accounting. Data Submission = Arkansas and Virginia were created under a voluntary claims submission model and subsequently gained authority for mandatory data submission. Funding = Virginia was funded through industry contributions prior to receiving a state appropriation in 2019; Wisconsin received state grants for APCD development and tasks but no longer receives state funding. Linkages = Registry and EHR data have been linked with Colorado APCD data in exploratory studies; Maine plans to link vital records and registries pending legislative authorization; Wisconsin plans to link APCD and EHR data through a collaborative venture. Analytics: Maine includes external users of APCD data; Utah plans to acquire a low-value care analytic tool pending funding. See "How This Study Was Conducted" for notes on State Rank or Grade.

Several states also collect, and maintain separately, nonclaims data to support extended use cases.

- *Alternative payment models.* Following the lead of Massachusetts and Oregon, Colorado is collecting information on insurers' use of alternative payment models, such as capitation, to track value-based payment and better estimate total health care spending.
- **Prescription drug pricing.** Maine recently required pharmaceutical manufacturers to report cost information when the price of a prescription drug increases by more than 20 percent.<sup>22</sup> The state may request additional component cost information from wholesale distributors and pharmacy benefit managers to understand cost drivers along the drug supply chain. Colorado requires insurers to report the aggregate dollar amount of prescription drug rebates granted by pharmaceutical manufacturers.<sup>23</sup> Policymakers can use this information to pinpoint drivers of rising drug costs and assess whether regulation of industry practices is warranted.<sup>24</sup>
- *Provider financial performance*. Maine and Virginia collect information on the financial performance of hospitals in their states, which allows a broader understanding of their operating efficiency and profitability.

#### Exhibit 6. Medical Claims Data Elements Collected by the Maine APCD

- Type of product (e.g., HMO, POS, indemnity)
- Type of contract (e.g., single, family)
- Coverage type (e.g., self-funded, individual, small group)
- Dates (e.g., birth, service, paid)
- Patient demographics (e.g., age, gender, residence, relationship to subscriber)
- Service codes (e.g., revenue, diagnosis, procedure, drug)
- Service/prescribing provider
- Billing provider
- Plan payments and member copay, coinsurance, deductible amounts
- Facility/bill type

Source: Maine Health Data Organization

The more transparency there is in prescription drug pricing, the more we'll be able take targeted action to help reduce the costs of these life-supporting medications. ... The report issued last year by the Maine Health Data Organization is a powerful tool that lets Mainers and officials know what pharmaceutical companies are charging patients.

**Maine Senator Eloise Vitelli** 

#### **Data Linkages**

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APCD administrators and stakeholders are exploring opportunities to link claims with other types of data to capture a more complete record of patient populations, risk factors, and services provided as well as to allow a fuller understanding of the relationships between costs and the quality and outcomes of care (Exhibits 5 and 7).

Some linkages do not require fully identifiable data. For example, standardized data on quality of care can be linked by provider with average or median negotiated prices from the APCD, to offer insight on value in transparency tools. APCD and census data can be linked at the ZIP code level to study how socioeconomic factors (e.g., race, ethnicity, income) and social determinants of health (e.g., housing) influence health care utilization and spending.<sup>25</sup> Hospital encounter data, such as the records of patients who are uninsured or pay for care out of pocket, can fill gaps in APCD data.

In states that collect and allow protected uses of identifiable data by their APCD, claims may be linked by individual to other data systems—such as birth and death records—in studies subject to protocols to protect patient privacy. Similarly, clinical data from electronic health records (e.g., the results of blood tests to control diabetes) and disease registries (e.g., cancer stage and survival information) can augment claims data to construct a more

#### Exhibit 7. Example of APCD Data Linkages



Source: Author's analysis. APCD = All-Payer Claims Database.

complete treatment history including the costs of care and its outcomes.<sup>26</sup>

While feasibility studies have demonstrated that linked datasets offer potential analytic synergies, interviewees cautioned that technical, administrative, and legal hurdles must be surmounted to establish durable ongoing linkages—especially when data sources are maintained by separate organizations with potentially disparate missions and goals.<sup>27</sup>

#### Analytics

The potential of an APCD is more fully realized through analytic tools that allow rigorous uses of data (Exhibit 5; see the companion report for details on such uses). For example, several states use episode-of-care "grouper" tools to report on the bundled cost of common procedures such as knee or hip replacements, including services that are typically received before and after the procedure (Exhibit 8).<sup>28</sup> Bundled costs offer a useful way for consumers to compare providers when deciding where to receive elective procedures. These tools can also be used by stakeholders to assess the opportunity for developing episode-based payments and referral networks that provide patients with higher-quality and lower-cost care.

#### **Protecting Data Privacy**

States undertake a variety of measures to prevent the unauthorized use or disclosure of protected health information, such as a requirement that data recipients sign and comply with a data use agreement specifying permitted uses of the data.<sup>29</sup> Some states provide data submitters with software to "hash" patient identifiers into a key code so that records can be linked over time while maintaining patient anonymity. Other states collect identified data but require that it be encrypted and that disclosures are restricted to comply with privacy laws based on specific uses and assurances. Maine, for example, defines three levels of data disclosure, with increased oversight and restriction at each level: 1) de-identified data; 2) a limited dataset that includes some identifiers necessary for research; and 3) a fully identified dataset limited to purposes of public health or health care treatment, payment, and operations.

#### Exhibit 8. Example of Episode-of-Care Analysis

Colonoscopy Episode Payment = \$1,800\*

#### **Pre-Procedure**

Costs associated with care before the procedure (tests, doctor's visits, etc.)

#### **Procedure Cost**

Costs associated with the procedure include all facility, provider, and ancillary (lab tests, medications administered, etc.) fees



Source: Center for Improving Value in Health Care.

\*Note: Numbers displayed were developed for this example and do not reflect actual costs.

#### **Data Restrictions**

Many states, for various reasons, restrict the use or disclosure of some data elements or types of data. For example, New Hampshire permits the use of Medicaid data only for research purposes approved by the state's Medicaid director. Minnesota prohibits the identification of specific providers or payers in analyses using APCD data. Virginia and Wisconsin normalize payment amounts to prevent the comparison of providers based on negotiated rates, while still allowing the analysis of regional averages in cost and of differences by type of insurance or payer.<sup>30</sup> Maine prohibits data recipients from computing the ratio of billed charges to amounts paid for a type of service rendered by any individual health care payer, facility, or practitioner. Each of these restrictions limits the utility of the APCD in ways that prospective data users must assess in relation to their specific needs and purposes.

#### **INSIGHTS AND LESSONS LEARNED**

Establishing an effective state APCD requires engaging with stakeholders to obtain their support, determining a suitable governance structure, securing sustainable funding, setting realistic implementation timeframes, and maintaining the APCD's integrity by ensuring data quality and analytic rigor while protecting data privacy and objectivity. 1. Engage with Stakeholders. APCD leaders were unanimous in highlighting the importance of engaging with their stakeholders—including data submitters and users, and those affected by the APCD's use—through formal and informal means. "Initial and ongoing stakeholder engagement is critical to addressing challenges regarding legislation, funding, technology and staffing," says Michael Lundberg, CEO of Virginia Health Information. "We believe that data moves at the speed of trust and not only do we have to be good stewards of the data, but we must also continually cultivate and build trust in our work with the partners and stakeholders we support," says Ana English, CEO of Colorado's Center for Improving Value in Health Care.

**Post-Procedure** 

Costs associated with care after

the procedure (physical therapy,

medications, follow-up visits, etc.)

2. Determine a Suitable Governance Structure. Unique contextual factors in each state will shape decisions about governance. State agency administration of an APCD offers a consistent approach to state data collection efforts and may promote a holistic scheme for using data resources. An independent APCD administrator or authority can be a neutral convener of stakeholders, one step removed from political influence. While a voluntary approach may offer a feasible way for some states to create an APCD, it involves a trade-off between flexibility and

data completeness; in Arkansas and Virginia the voluntary model was a stepping stone to a state-authorized model that improved data completeness.<sup>31</sup> Whatever approach is taken, states should consider that complex arrangements can create challenges for efficient administration of an APCD.

**3.** Secure Sustainable Funding. The mission and purposes of an APCD will determine what funding approaches are feasible and prudent. Colorado found that it could not sustain a robust APCD solely on grants and data licensing fees while pursuing a mission emphasizing the public good and the state's interests. Consequently, it has pivoted toward acquiring state funding to support a large portion of its operating costs. In contrast, the Wisconsin Health Information Organization has funded its APCD from industry fees and subscriptions in support of health system performance improvement rather than a public policy agenda. Few other APCDs have used this approach.

Commentators say that state APCDs are generally underfunded and under-resourced for the task that states have set for them.<sup>32</sup> Indeed, some APCD leaders say they are "scratching the surface" or "touching the tip of the iceberg" in terms of the APCD's potential. The current economic downturn is constraining state budgets, which is putting state funding for APCDs at risk. State APCDs will be challenged to demonstrate their relevance by contributing vital information to help guide shifts underway in the health care system.

4. Set Realistic Implementation Goals and Timeframes. Leaders emphasized the need to decide in advance the purposes and products of the APCD. Because vendors have improved their capabilities, new APCDs may benefit from faster implementation than in the past. Nevertheless, APCD leaders noted that even after an APCD is technically operational, it takes time for data submitters to set up data transfers as well as for APCD staff to refine processes to ensure data quality and build analytic capabilities. This process can be shortened for multistate and national insurers when

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As part of each APCD study, we are assessing data quality and looking for potential improvement opportunities.

Stefan Gildemeister Director of Health Economics, Minnesota Department of Health

states adopt common data submission standards. In any event, states and other funders should realize that creating an APCD represents a long-term investment, the value of which may take several years to bear fruit.

- 5. Create Processes to Maintain the APCD's Integrity. APCD administrators stress the importance of the quality and timeliness of APCD data and, to serve the growing demand for information, their own analytic capacity.<sup>33</sup> "We initially thought everyone was just going to want datasets. The reality is that there is a very limited group of individuals and researchers that can analyze complex claims data. So, we've had to build internal analytic skills and tools to analyze the data. And the more that we're working with the data, the more we've come to realize where we have gaps and opportunities to improve the data," says Colorado's English.
- 6. Learn from Other States. APCD leaders urge their colleagues to learn from one another's experiences, particularly from other states with similar objectives and common vendors. Several pointed to examples of how sharing learning or approaches from state to state had saved considerable effort.<sup>34</sup> On the other hand, one APCD leader also advised taking care to consider the need for adapting another state's approach to meet the unique circumstances of the home state. To advance common goals with constrained resources, states may wish to examine the opportunity to purchase shared services in support of their APCDs in future.

#### **HOW THIS STUDY WAS CONDUCTED**

**Data Collection and Analysis:** We conducted semistructured interviews with APCD leaders in each state and with select stakeholders (e.g., legislator, employer, Medicaid official) in some states. Interviews were recorded (with permission) and transcribed. Data derived from interviews and documentary sources were organized in cross-case displays for topical content analysis.<sup>35</sup> Findings were validated and refined based on a comparison with other published literature and through review by interviewees.

**Site Selection**: Based on a literature scan and expert advice, we selected eight states (Exhibit 1) whose APCDs are characterized by diverse approaches and contexts. The APCDs, which have been in operation for four to 17 years, were also selected to highlight relatively advanced uses of data. We excluded some states that are the subject of other research (Massachusetts, Rhode Island), that only recently implemented an APCD (Delaware), or that have a unique policy context (all-payer rate setting in Maryland). The states we chose represent the U.S.'s New England, Midwest, South, and West regions.

**Contextual Environments:** Study states represent a variety of markets and public policies. Collectively, they tend to perform better than average among all states on rankings of health system performance (median 12; range 3 to 47), small group insurance market competition (median 16; range 1 to 36), and ensuring that information is available to the public (median 13; range 1 to 37), as well as on an assessment of health care price transparency laws (median grade C; range A to F). All but Wisconsin have expanded Medicaid under the Affordable Care Act. These factors suggest that most study states are amenable to adopting health reforms and policies to promote health system improvement, which may have influenced the creation of an APCD.

State Ranking or Grade	Ark.	Colo.	Maine	Minn.	N.H.	Utah	Va.	Wisc.	Average	Median
Health System Performance (1)	47	9	12	3	10	11	29	12	17	12
Insurance Market Competition (2)	26	12	17	14	32	36	5	1	18	16
Ensuring Data Is Available for Use (3)	17	1	4	10	37	11	14	35	16	13
Healthcare Price Transparency (4)	D	В	A	С	А	D	С	F	С	С
Expanded Medicaid Under ACA (5)	Y	Y	Y	Y	Y	Y	Y	Ν	Y	Y

Sources: (1) The Commonwealth Fund, Scorecard on State Health System Performance (2019) (1=highest performing state). (2) Kaiser Family Foundation, State Health Facts: Small Group Insurance Market Competition, Rank on Herfindahl-Hirschman Index (1=most competitive market). (3) Center for Data Innovation, The Best States for Data Innovation (2017). The rank is a composite of nine indicators (1=best at making data available for public use). (4) Catalyst for Payment Reform and the Source on Healthcare Price and Competition, "2020 Report Card on State Price Transparency Laws," 2020. (5) The Commonwealth Fund, Medicaid Expansion Status, 2019.

#### NOTES

- The Urban Institute, "State and Local Expenditures: How Have State and Local Expenditures Changed Over Time?" (Urban Institute, n.d.); Manatt Health, "Understanding the Fiscal Impact of COVID-19, the Economic Downturn, and Recent Policy Changes" (Woodrow Wilson School of Public and International Affairs, June 5, 2020).
- The share of U.S. workers with out-of-pocket health care expenses (excluding premiums) greater than 10% of their income increased from 10% in 2003 to 29% in 2018; see Sara R. Collins, Herman K. Bhupal, and Michelle M. Doty, *Health Insurance Coverage Eight Years After the ACA* (The Commonwealth Fund, Feb. 2019).
- 3. Some writers use the term *Multi-Payer Claims Database* to reflect the fact that a database may not include all payers. We use the term *All-Payer Claims Database* to reflect common usage and the aspiration of these tools.
- 4. The APCD Council, Interactive State Report Map, accessed May 1, 2020.
- Denise Love, William Custer, and Patrick Miller, *All-Payer Claims Databases: State Initiatives to Improve Health Care Transparency* (The Commonwealth Fund, Sept. 2010); Jennifer Ricards and Lynn Blewett, *Making Use of All-Payer Claims Databases for Health Care Reform Evaluation*  (U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, July 2014); Stephanie Cohen and Lynn Quincy, *All-Payer Claims Databases: Unlocking Data to Improve Healthcare Value* (Altarum Healthcare Value Hub, Sept. 2015); Josephine Porter and Denise Love, *The ABCs of APCDs* (California Health Care Foundation, Nov. 2018).
- 6. Lisa Waugh and Douglas McCarthy, *How the Massachusetts Health Policy Commission Is Fostering a Statewide Commitment to Contain Health Care Spending Growth* (The Commonwealth Fund, March 2020).

- For a fuller discussion, see Erin Bartoloini and Rebecca Paradis, *All Payer Claims Databases: Unlocking the Potential* (Network for Excellence in Health Innovation, Dec. 2014).
- Research using data from the Massachusetts APCD found that harnessing transparent price information to drive care to lower-cost providers could produce significant savings; see Anna D. Sinaiko, Pragya Kakani, and Meredith B. Rosenthal, "Marketwide Price Transparency Suggests Significant Opportunities for Value-Based Purchasing," Health Affairs, 38(9) (Sept. 2019):1514-22.
- For an in-depth guide to the creation of an APCD, including its technical build, see Josephine Porter et al., *All-Payer Claims Database Development Manual: Establishing a Foundation for Health Care Transparency and Informed Decision Making* (The APCD Council and West Health Policy Center, Feb. 2015).
- 10. The Colorado and Virginia APCDs are considered public-private partnerships because they were initially privately funded to carry out a legislatively authorized public purpose. Maine's ACPD was developed by a legislatively authorized publicprivate partnership between a state agency—the Maine Health Data Organization (MHDO)—and the nonprofit Maine Health Information Center (now known as OnPoint Health Data); MHDO later assumed full authority for its operation.
- For a detailed analysis of state approaches, see Tanya Bernstein and Kristin Paulson, *Funding for APCD's* via CMS Medicaid Match: Examples from Two States (Freedman Healthcare, Feb. 20, 2018).
- 12. Virginia's APCD was self-funded by industry contributions under a voluntary claims submission model until 2019, when the state appropriated funds to support a mandatory claims submission model.
- The Wisconsin APCD is entirely funded by fees paid to WHIO for products and services. Data submitters are offered free or discounted access to some tools or data.

- 14. Federal grants have been awarded to several state APCDs through the Centers for Medicare & Medicaid Services including the Center for Consumer Information & Insurance Oversight Cycle III Rate Review Grants and the Center for Medicare & Medicaid Innovation State Innovation Model program and Transforming Clinical Practice Initiative.
- 15. States typically set a threshold for claims data submission, such as a minimum number of insured lives (e.g., 2,000 lives in Arkansas) or a minimum annual dollar amount of medical claims (e.g., \$3 million in Minnesota). State residents may include dependents such as college students that live out of state.
- 16. In Wisconsin, health plans that serve the state employee benefit plan are contractually required to submit claims data on their enrollees to the APCD; some other health plans as well as a coalition of selfinsured employers also voluntarily submit data.
- 17. State APCDs can obtain Medicare data for research purposes through a state's application to the Research Data Assistance Center, or for use in provider performance reporting by becoming certified as a Qualified Entity by the Centers for Medicare & Medicaid Services. WHIO plans to include Medicare claims in the Wisconsin APCD by year end.
- United State Supreme Court, Gobeille v. Liberty Mutual Insurance Co., Inc. For an analysis of the ruling, see Gregory D. Curfman, "All-Payer Claims Databases After Gobeille," *Health Affairs Blog*, March 3, 2017.
- 19. Self-insured employers typically contract with third-party administrators (TPAs) to manage their employee benefit plans. The TPA submits claims data to the APCD on behalf of employer-clients that authorize them to do so. TPAs sometimes fail to comply with directives to submit data to APCDs, requiring compliance efforts by APCD staff in cooperation with the employer.

- 20. For example, the Colorado APCD included claims data for 595,000 individuals covered by self-insured employer plans in 2018, representing 31% of the estimated number of self-insured lives in the state. Motivations for voluntary submissions vary. Some employers wish to use APCD data for their own analyses or to inform collective negotiations with providers or plans. Others participate out of a sense of contributing to the common good.
- 21. The APCD Council recently sponsored a collaborative effort to define a Common Data Layout to minimize the burden on payers that submit data to APCDs in multiple states. Virginia has adopted the Common Data Layout by statute and Colorado continues to harmonize its data submission regulation with the layout. Some observers argue that states should strictly adhere to a common standard, while others contend that states need flexibility to meet specific state policy objectives. For example, Colorado requires health plans to submit the "metal tier" of plans sold on the state marketplace to allow research on associations between coverage, utilization, and costs.
- 22. Maine Health Data Organization, Chapter 570, Uniform Reporting System for Prescription Drug Price Data Sets, effective Feb. 4, 2020.
- 23. A forthcoming report from the Colorado APCD will describe how prescription drug rebates work, how they promote utilization of selected drugs, the size of rebates, and their impact on trends in prescription drug spending.
- 24. For example, some states have enacted legislation requiring pharmacy benefit managers (PBMs) to disclose whether prescription drug rebates are retained by the PBM or passed through to insurers and consumers; see National Academy for State Health Policy, *State Actions to Address Rising Prescription Drug Costs* (Jan. 2020).
- Victoria Udalova, "Enhancing Health Data (EHealth) Initiative at the U.S. Census Bureau," National Association of Health Data Organizations 34th Annual Meeting (Nov. 7, 2019).

- 26. The Wisconsin Health Information Organization and the Wisconsin Collaborative on Healthcare Quality are planning a joint venture to link claims data from the APCD with clinical data from electronic health records to produce more accurate and comprehensive comparative reports on cost and quality of care at the provider level. For additional examples, see Jessica Toth, "The Curious and Complementary Relationship of the CO APCD and Electronic Healthcare Data from UCHealth," National Association of Health Data Organizations 34<sup>th</sup> Annual Meeting (Nov. 6, 2019); Mia Hashibe et al., "Feasibility of Capturing Cancer Treatment Data in the Utah All-Payer Claims Database," JCO Clinical Cancer Informatics (Oct. 2019), 3:1-10.
- 27. In Arkansas and Virginia, APCD administrators are also responsible for managing their states' Health Information Exchanges (HIEs), which may facilitate future efforts to link clinical and claims data.
- 28. Episode grouper tools used by study sites include Prometheus Analytics, Optum Symmetry Episode Treatment Groups, and the Milliman MedInsight Health Cost Guidelines Grouper. Some tools also report on preventable complications and their costs. See National Quality Forum, Evaluating Episode Groupers (NQF, Sept. 5, 2014).
- 29. For a detailed analysis of state approaches, see Alyssa Harrington, *Releasing APCD Data: How States Balance Privacy and Utility* (Freedman Healthcare, March 2017).
- 30. Virginia Health Information reports a standardized proxy reimbursement amount based on allowed amounts but masked using Milliman's Global RVU methodology. The conversion factor reflects allowed and paid charges within the Commonwealth of Virginia—a blend of all the allowed dollars by all the contributing insurance carriers.

- 31. The number of insured lives included in the Virginia APCD increased by approximately one million after the state mandated claims submission and expanded Medicaid.
- Lovisa Gustafsson, Shanoor Seervai, and David Blumenthal, "The U.S. Can't Fix Health Care Without Better Price Data," *Harvard Business Review* (May 30, 2019).
- 33. With funding from the federal Agency for Healthcare Research and Quality, the National Association of Health Data Organizations sponsored a Data Quality Forum and a Data Quality Benchmarking Pilot Project to help state APCDs assess their capabilities and identify areas for improvement; see Current and Innovative Practices in Data Quality Assurance and Improvement (NAHDO, 2019).
- 34. The National Association of Health Data
  Organizations (NAHDO), a nonprofit membership organization, sponsors events and workgroups to facilitate state-to-state learning about APCDs. The APCD Council is a learning collaborative of government, private, nonprofit, and academic organizations convened and coordinated by the Institute for Health Policy and Practice at the University of New Hampshire and NAHDO. The Council offers a Learning Network to assist states in the development and deployment of APCDs.
- 35. Mathew B. Miles and A. Michael Huberman, "Cross-Case Displays: Exploring and Describing," in *Qualitative Data Analysis*, 2nd ed. (Sage Publications, 1994).

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See the second report in this series for insight on the uses and benefits of APCDs.

See the companion state profiles for more information on each state's APCD.





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