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# Realizing the Promise of All Payer Claims Databases

## A Federal and State Action Plan

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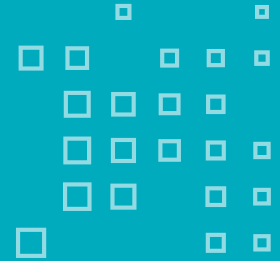


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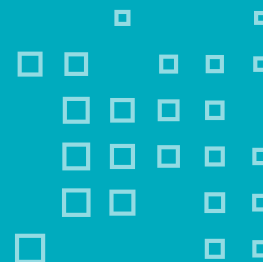
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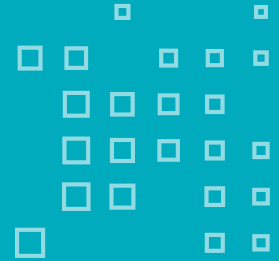
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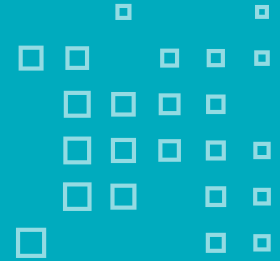
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America spends more on health care per person than any other developed country, only to have the lowest life expectancy among them.<sup>1,2</sup> Despite our expenditures—now one out of every five dollars of national income<sup>3</sup>—our system’s shortcomings are abundant. Nearly half of American adults have difficulty affording care, and four in ten report delaying or forgoing care due to cost.<sup>4</sup> Racial and ethnic health disparities in our country are pervasive<sup>5</sup> and newly compounded by COVID-19.<sup>6</sup> And in a system where coverage is often linked to employment, in the first months of the public health emergency, an estimated 14.6 million workers and their family members lost their employer-sponsored insurance.<sup>7</sup>

We are not alright. In a fragmented system of care regulated by a patchwork of federal and state entities, too often we do not have a comprehensive and cohesive view of how our systems of health are performing and where they are failing—a prerequisite for developing effective and targeted solutions for the systems’ shortcomings. So we survey the damage (see citations above) and often place the burden of assessing and fixing the systems’ gaps on states: the 50-plus-one striving to see the fire, contain the fire, fight the fire from our 50-plus-one rooms while the house is burning. State policymakers—from California to Arkansas, Florida to Massachusetts—strive to meet this challenge every day, investing in health data resources to better understand their local markets and developing local policy and program solutions to stem health care cost growth, improve care delivery and quality, respond to public health needs, and keep their most vulnerable protected from harm. States do what they can, as they can, to stave off a national burn that keeps gaining ground.

But to solve national issues, we need national solutions—or at a minimum, coordinated state action. We need information about how our systems of health are operating, as they are operating, across state borders and populations and across payers and providers in order to understand where these systems are succeeding and failing. We need national data for us to collectively address our national concerns about health care coverage, access, cost, quality, and impact—our return on investment for supporting the best-funded health care system in the world.

This paper proposes actions that the federal government can take in partnership with states to strengthen our local and national health data capacity to support evidence-based policymaking. It proposes building from existing state health data infrastructure, APCDs—cross-payer administrative, claims, and encounter data repositories—that are now stewarded by or planned for development in nearly half of the states, including our four largest: California, Texas, Florida, and New York. It also offers an expanded state APCD operating model that seeks to resolve present limitations while creating a national health data resource that would be jointly governed by state and federal representatives, health care purchasers, and consumer privacy advocates. Policymakers, researchers, purchasers, and consumer advocates may use this new health data capacity to better understand and address cross-state health system challenges—from regional health disparities to behavioral health service deserts to system cost drivers—and establish a common, data-based foundation on which future reforms and actions may be shaped, debated, pursued, and evaluated.

While this paper was informed by personal experience—from my days as an APCD programmer to my role on the board of NAHDO to my daily work supporting state health and human service leaders across the country to better employ their data and analytic resources—its findings are equally attributable to our



generous health data community. Over 40 of our country’s leading federal, state, industry, and academic health data leaders took the time to provide feedback on the paper’s concepts and proposals and shared their smart and sharp insights on its content, making the end product that much stronger. To each, I am grateful.<sup>i</sup> I am also thankful to my Manatt colleagues for their input and contributions throughout the paper development process, including **Jonah Frohlich**, senior managing director; **Amy Zhan**, manager; **Michael Budros**, manager; and **Joel Ario**, managing director, who has been an invaluable mentor and partner through our state health data projects over the past five years. This paper would not have been possible without support from the **Robert Wood Johnson Foundation** and, specifically, **Kathy Hempstead**, a persistent champion for building effective state health data capacity to support more-informed policymaking. It would also not have been possible without my incredible wife, for managing more than her share of childcare during weekends as I worked on this “six to ten page paper.” And finally, I would be remiss not to recognize the incredible, pathbreaking work of our state health data leaders who, through demonstrating the value of APCDs over the past 20 years, have made the case for broader investments in these resources and the health data organizations that steward them.

Through this paper, we offer a pathway for policymakers to strengthen our national health data infrastructure to support the public good. It is not the only path forward, or as some may argue, the best path forward. To the inevitable discussion of its deficiencies, I ask that we not lose sight of the incontrovertible need for us to do more to build our capabilities to fix a system that is objectively not working for most Americans and the foundational and prerequisite role of data to help us shape and realize our aspirations for a more effective, efficient, and equitable system of health.



Kevin Casey McAvey

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<sup>i</sup> See [Appendix](#) for list of reviewers and contributors.

## Executive Summary

In 2020, health care spending in the United States increased by nearly 10% to reach \$4.1 trillion, or 20% of the U.S. economy.<sup>8</sup> Yet, for an industry powered by data and foundational to the health and well-being of our nation, policymakers, regulators, and other public stakeholders often lack comprehensive, cohesive, and timely information about its operations and performance, including:

- What services it delivers, at what cost, and to what end
- Where service inequities and health disparities persist across and among populations
- Which services and entities are driving health care cost growth
- Why our systems of health, the costliest in the world, continue to produce life expectancies below those of peer countries<sup>9</sup>
- How our federal and state policy and program reforms have impacted the lives of Americans

Reflecting our nation's fragmented health care delivery system and its patchwork of federal and state regulatory authorities, our nation's health system data<sup>ii</sup> is also siloed, scattered, and incomplete. State insurance departments, Medicaid departments, Affordable Care Act (ACA) Marketplaces, and state employee health benefit programs, for example, each collect and monitor data for the plans, providers, and individuals under their respective authorities, providing each a relatively narrow view into the dynamic markets they serve. State departments' fragmented and siloed views of health systems often limit their ability to effectively pursue broader regulatory goals—such as increasing coverage, containing costs, and improving service quality—and foresee, and possibly prevent, unintended impacts of potential regulatory actions and can make them vulnerable to industry gaming, as regulated entities often have more market information than do regulators.

To address local information gaps, state policymakers and regulators from across the country—and across the political spectrum—have invested in APCDs, which can offer unique insights into local market dynamics and operations.

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<sup>ii</sup> This paper focuses on health system administrative data, claims, and encounters and records of services rendered to patients by providers, which typically include additional information on patient diagnoses and payment amounts between payers and providers.

## State APCDs

State APCDs are market-wide repositories of public and private payer health care claims and encounter data, including: records of health care service payments that provide contextual information about the individuals served and their diagnosed conditions. State APCDs have proliferated since they were first established in the early 2000s. Eighteen states presently have an APCD, and at least six others have an APCD in development.

State APCDs can provide users with broad and longitudinal, cross-payer insights into health system performance and changing population health, and they are used by policymakers to inform health care and payment reform design as well as to support market transparency. In recent years, state APCDs have been used to:

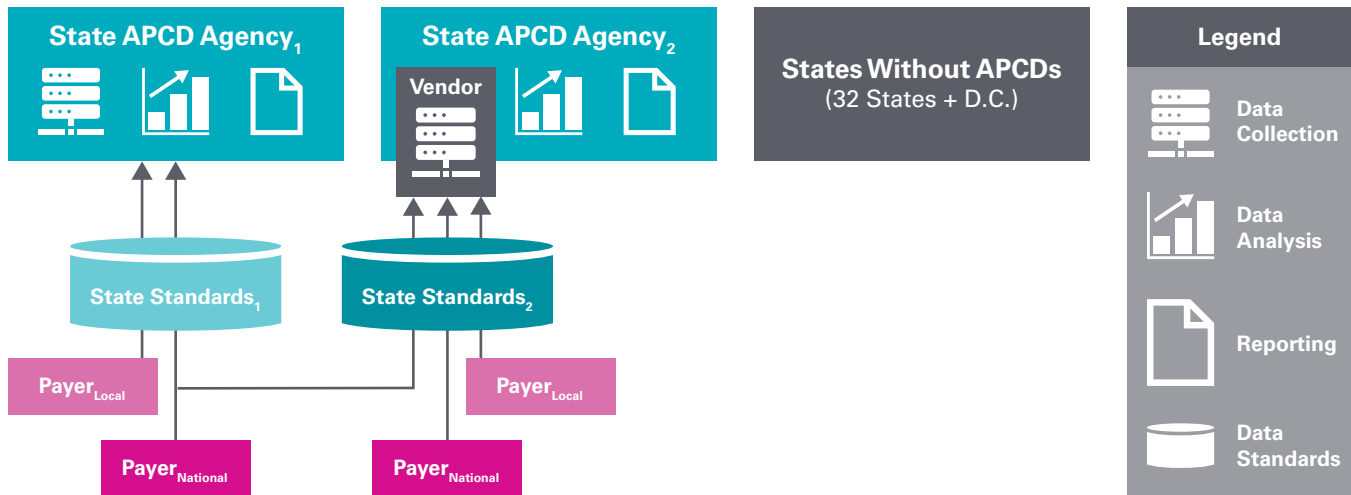
- Create and monitor baseline statistics of state health insurance coverage, service utilization, service costs, cost trends (including priority services such as primary care and behavioral health care), and health outcomes.<sup>10</sup>
- Identify inequities in health system access and use as well as disparities in health condition prevalence and outcomes.<sup>11</sup>
- Support regulatory oversight of payers and providers, from monitoring network adequacy and mental health parity to assessing the cost impact of industry consolidation.<sup>12</sup>
- Identify health system failures—including coverage disruptions, excessive cost growth, service price variation, and preventable emergency department (ED) visits—to inform policy responses.<sup>13</sup>
- Facilitate an understanding of whole-person health needs by linking data for individuals covered by more than one payer (e.g., Medicare/Medicaid dual-eligible analyses) and bridging health and social service/public health data sources (e.g., opioid disorder prevalence analyses).<sup>14</sup>
- Provide purchasers, payers, and consumers with health service cost and quality information to make informed health coverage purchasing and network design decisions.<sup>15</sup>

By 2025, at least half of all states, including the nation's four largest, will have an operating APCD and benefit from the information these resources can provide. However, the current state APCD operating model, originally designed to support the needs of several smaller states, was not intended to serve as a national health data blueprint and has several limitations that prohibit important local and national use cases.

## Opportunities to Enhance State APCD Use and Usefulness

Presently, state APCD agencies collect membership, claims, and provider data from national and local health care payers licensed to operate in their markets and for which they have regulatory authority or voluntary cooperation to collect such information ([Exhibit 1](#)). Payer data is collected, as often as monthly, in five to nine different files and in accordance with each state's data collection standards, practices, and processes. Files may comprise tens of millions of records, which states must review for integrity before linking them with previously received data to create a longitudinal dataset (which allows for understanding health system and population changes over time). Each state pursues its own APCD research and reporting priorities using the data it receives.

**Exhibit 1: Current State APCD Operating Model**



While state APCDs have demonstrated their capabilities to provide state policymakers and regulators, among other data users, with deep insights into local markets, the current state operating model has several limitations that can constrain their use and usefulness. These drawbacks include:

- **Missing data for key populations and services:** Federal regulations limit the ability of state APCD agencies to collect data from self-insured plans covered by the Employee Retirement Income Security Act (ERISA) and from federally managed health care programs, creating data gaps for up to a third of state residents.
- **Inconsistent data collection and access requirements:** Each state APCD agency has its own protocols for how it collects, curates, and releases data, impeding cross-state data access and analytic comparisons.
- **Need for sustainable and adequate funding for state health data capacity:** State APCDs are often underinvested in resources and lack the level of sustained and reliable federal and state funding required to hire and retain top-flight talent and to invest in the foundational data, data management, and analytic infrastructure required to demonstrate their full capabilities.

With more than half of states not having an APCD, **national data collection gaps** limit national, regional, and cross-state analyses and benchmarking and result in new **state health information inequities** among states.

Addressing the shortcomings of America’s health care system requires an unobstructed view of how the system is operating, as it is operating, across populations, states, payers, and providers. It requires data that show how our health care system is making available, delivering, and paying for services, and how those services are impacting health outcomes. It requires system transparency and accountability. APCDs, clear-water basins of health care transactions, are protected state data resources that have the demonstrated capacity to support these objectives locally and—if properly invested in, harmonized, and built on—can address many of our nation’s health system information needs.

## Developing a New National APCD Operating Model

Throughout 2022, more than 40 federal and state policymakers, regulators, researchers, and other health data leaders were engaged to confirm the legal, regulatory, technical, and operational root causes of these state APCD limitations and to design and test potential alternative APCD operating models that could resolve them—to the benefit of current and future state APCD users. Solutioning was guided by nine principles that were identified by stakeholders as essential to the success of any model ([Exhibit 2](#)).

### Exhibit 2: Guiding Principles (Summary)

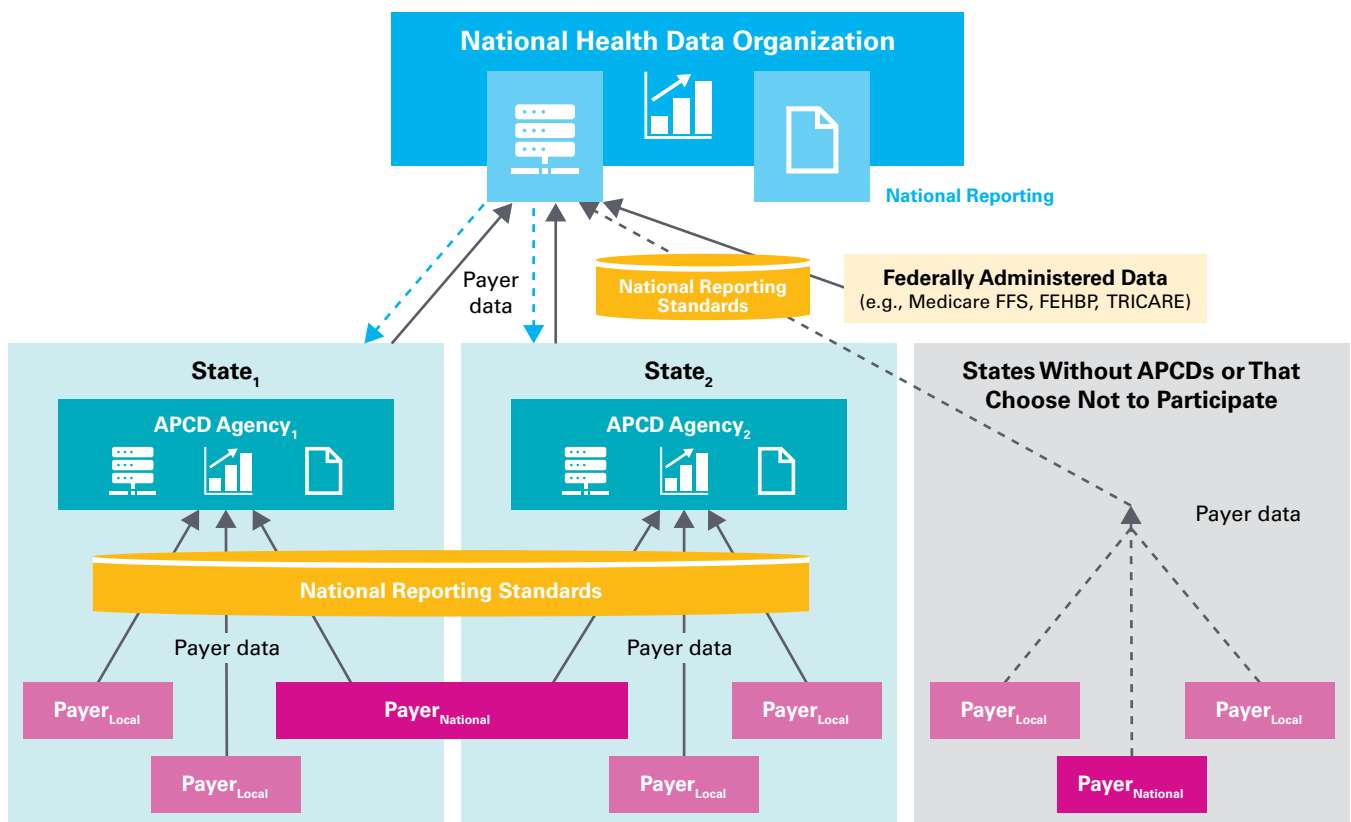
Guiding Principles for National APCD Operating Model Design	
1.	<b>Health system data is a public good.</b> Administrative health data is a public good that can and should be used to support health system oversight to benefit consumers.
2.	<b>States must maintain APCD data stewardship.</b> Many state APCDs are now high-functioning data resources. Any alternative APCD model should not jeopardize existing state operations or alter participating states’ roles as the primary APCD data collectors and owners.
3.	<b>Federal help is required to address APCD limitations nationally.</b> Federal support and regulatory action are needed to resolve state APCD data completeness issues.
4.	<b>Data standardization requires data governance.</b> A more formal ad shared system of data governance, between states and the federal government, would be needed to harmonize and manage national APCD data standards.
5.	<b>Strong state health data use requires reliable and sustained funding.</b> States are responsible for overseeing increasingly complex and interconnected health care markets but do not have commensurate resources to build and sustain the data and analytic capacity necessary to meet the needs of modern, data-driven regulatory agencies.
6.	<b>Data users and changemakers need better access to APCD data.</b> Potential users of state APCD data must navigate complex, lengthy, and individual data application and access processes to acquire APCD data. For APCDs to be effective tools of system change, their data needs to be collectively easier to acquire and integrate.
7.	<b>National health system transparency is needed.</b> A national APCD is required to provide insight into national and regional health system, population health, and public health issues.
8.	<b>Payer reporting burden must be addressed.</b> The administrative burden payers confront for transforming and submitting data differently to each state APCD is real, costly, and set to grow. Greater APCD data standardization can alleviate payer burden and strengthen the case for national self-insured data collection.
9.	<b>National opportunity to strengthen APCD data protections.</b> State APCDs steward highly sensitive patient-level information that must be protected from unintended access and use. Any systemic APCD system change should strengthen data security and privacy standards across state APCDs nationally.

Stakeholders identified and assessed a number of alternate APCD operating models, including six discussed in this report, and recommended the pursuit of a model that would strengthen and build from the existing state-based APCD structure to create new national health data capacity: the “Federally Facilitated State Data Partnership” model ([Exhibit 3](#)). In this model, states would continue to serve as APCD data owners and have the option of participating in a national health data compact. As part of the compact, states would continue to collect payer data locally but in alignment with new national data standards and practices. States would then share collected data with a new national health data organization (HDO). In exchange for their participation, states would receive federal financial support and be granted new access to federally regulated and administered health data, such as data for the ERISA-preempted self-insured. For states without an APCD or that choose not to participate, the National HDO would collect APCD data directly from payers operating

in those states to complete a national picture. The National HDO would provide national policymakers, regulators, and researchers—as well as states—with a new, centralized resource for cross-state health system administrative data.

The National HDO would be contracted and funded by, but sit outside, the federal government and be governed by a combination of federal, state, and consumer privacy representatives in a public and transparent manner. The National HDO governing body would be responsible for overseeing the organization and its operations as well as approving national APCD data standards, baseline privacy and security standards, and the purposes for which the national APCD may be accessed and used.

**Exhibit 3: Proposed National APCD Model: Federally Facilitated State Data Partnership**



The model would create new national and cross-state data access, comparability, and analytic capacity while preserving state APCD data ownership.

## Establishing a Federal and State APCD Action Plan

States cannot support APCD system change alone despite state data submitters, collectors, and users benefiting from the more complete data—and the stronger local analytic capacity—that would result. Federal leadership and sustained partnership are required to realize a national APCD model that strengthens state health data infrastructure, incentivizes cross-state data harmonization, and builds the centralized data collection, analysis, and governance capacity needed to support a national, coordinated system of administrative health data reporting and use. The federal government, through its Agency for Healthcare Research and Quality (AHRQ), has previously played a similar role in rationalizing state hospital discharge data collection and reporting, creating a cornerstone national health data resource in its Healthcare Cost and Utilization Project databases.

The effective implementation of the recommended national APCD operating model will require federal and state stakeholders to work together to establish the following:

1. **A National HDO** that is viewed as a trustworthy, independent, and protective steward of the nation’s health care administrative data.
2. **A federal-state-consumer governance partnership** to oversee and direct National HDO activities, including the alignment of uniform data standards and practices across participating states.
3. **A plan to resolve self-insured reporting barriers** to ensure states have access to the data necessary to oversee their markets, and purchasers (and other users) have data to compare across markets.
4. **A source of federal health data funding for states** to support model implementation and sustain permanent and robust state or regional health data collection and analytic infrastructure.
5. **A national compact on APCD data privacy and security** to set baseline data privacy and security protections for the National HDO and participating states.

Establishing a national, coordinated APCD operating model would provide state HDOs with new data access and funding support, enhancing the value they can provide to local stakeholders; reduce the reporting burden for multistate payers; and improve access to critical information about our health care system nationally. National, regional, and cross-state analytics and benchmarking would become possible and could be employed across states to foster health system transparency and accountability, monitor and respond to public health needs, and inform health care priorities and investment strategies.

As consumer health care cost growth accelerates in the wake of the national public health emergency, the importance of having comprehensive, flexible, and accessible health data resources—for state and national users—has never been clearer. Federally, the AHRQ has announced its intent to develop a “national level” APCD, designed in partnership with the Office of the Assistant Secretary for Planning and Evaluation, while Congress considers providing capacity-building funds to establish or enhance state APCDs. This paper was drafted with input from federal, state, and industry health data stakeholders to inform such actions and provide a clear road map for establishing an effective and sustainable national APCD infrastructure that builds on states’ existing health data strengths.

This paper seeks to provide health data stakeholders with contextual information about state APCDs (see Sections I and II) and the strengths and weaknesses of the current state APCD operating model (see Sections III and IV) before moving to an assessment of alternative models and recommendations for implementation (see Sections V and VI). The paper also cites a significant and growing body of literature about state APCDs, which itself may be valuable to readers.

Federal and state leaders now have the opportunity to recast our nation's APCD model to provide policymakers and regulators, purchasers, consumers, and researchers with the health system data and resources they need to counterbalance historical information inequities with one of America's largest, most critical, and most data-driven industries and to foster a more transparent and competitive market. It is for the public good that this paper seeks to elevate this issue for public attention and discourse.



## I. Introduction

In 2020, health care spending in the United States increased by nearly 10% to reach \$4.1 trillion, comprising nearly 20% of the U.S. economy and national income.<sup>16</sup> Yet, for an industry powered by data and foundational to the health and well-being of our nation, federal and state policymakers and regulators, researchers, purchasers, and consumer advocates often lack comprehensive, cohesive, and timely information about its operations and performance—how health care services are being utilized, by whom, to treat what conditions, at what cost, and to what end; where gaps exist in Americans’ access to needed health care services and quality care; where the system is succeeding and failing in improving the health of Americans, with life expectancies remaining well below those of peer countries; and whether federal and state policy and program reforms are having intended effects.<sup>17</sup>

Reflecting the fragmented nature of our nation’s health care delivery system and its patchwork of regulatory authorities, data about the system’s operations<sup>18</sup> are scattered among state and federal agencies—insurance departments, Medicaid agencies, ACA Marketplaces, public health departments, state employee health benefit programs—if collected at all, presenting each a narrow perspective of their otherwise expansive and dynamic markets.<sup>19</sup> State departments’ limited views of their health systems can constrain their ability to effectively pursue broader regulatory goals (e.g., increase coverage, contain costs, improve service quality) and foresee and prevent unintended impacts of regulatory actions, and can make them vulnerable to industry gaming, as regulated entities may have more complete market information than those that regulate them. To address their need for more comprehensive and cohesive information about market operations, state regulators are increasingly establishing market-wide data reporting requirements, including state cost growth benchmarking programs (now present in nine states) and health care administrative data repositories: state APCDs.<sup>20</sup>

State APCDs are market-wide repositories of public and private payer health care claims and encounter data, including: records of health care service payments containing contextual information about the individuals served, their diagnosed conditions, the plans that cover them, and the providers that serve them. Curated over time, APCDs can provide deep and longitudinal insights about population health and health system performance. State APCDs’ versatility to address a spectrum of use cases—from supporting market transparency to generating new insights into public health needs—has allowed them to proliferate nationally and across traditional political lines; in the next three years, the number of states with an APCD is expected to grow from 18 to at least 24, with California, Georgia, Indiana, and Texas all pursuing establishment.

APCDs can provide deep and longitudinal insights about population health and health system performance.

However, as discussed in this paper, the current state APCD operating model—developed in the early 2000s by several smaller states, and never intended to serve as a national blueprint—is not without limitations. State APCD agencies are preempted by federal law from collecting information about significant and important segments of their populations, like data for the ERISA-preempted self-insured.

State APCD data submitters (payers and third-party administrators (TPAs)), particularly those operating in multiple states, face significant reporting burdens as they translate their administrative data into multiple formats to meet states' unique data submission requirements. State APCD data users—from federal and state regulators to national researchers and purchasers—do not have easy access to cross-state information from state APCDs. They are required to navigate individual state applications and release restrictions to acquire data; even once they do acquire data, they must then invest significant effort in harmonizing data across divergent state collection standards (often resulting in their pursuing private data resources). And finally, while 18 states presently have access to an APCD to inform their policy- and decision-making, 32 states and the District of Columbia do not, creating new state health information inequities and prohibiting the type of national, regional, and cross-state benchmarking and analyses required to understand our cross-state health systems.

This paper seeks to provide all readers, regardless of their prior knowledge of APCDs, an understanding of what state APCDs are, why they are valuable, in what ways they are limited, and how we can invest in them to create stronger local—and new national—health data capacity.

- In [Section II](#) we describe what state APCDs are, the populations they comprise (and, especially since 2016, do not comprise), and how states are collectively and individually employing them to meet local information needs.
- In [Section III](#) we get more technical, discussing the current state APCD operating model, the important role that vendors play in supporting state APCD operations, how state APCDs balance data privacy and data utility, their sources of funding, and past federal attempts to support APCD development nationally.
- In [Section IV](#) we discuss opportunities to enhance state APCD use and usefulness for local and national users, speaking explicitly to the “gaps” state APCD submitters, users, and leaders confront—from missing and inconsistently collected data to sustained state health organization funding—and solution strategies federal, state, industry, and philanthropic leaders could pursue to resolve them.
- In [Section V](#) we outline principles—developed in collaboration with over 40 national health data leaders—to guide our assessment of six alternative APCD operating models to meet state, federal, and national health system data needs.
- In [Section VI](#) we recommend a pathway forward for federal and state leaders to realize a national system of health data collection, starting with investing in and strengthening our state infrastructure, then building a national system of data collection, reporting, and use.

Throughout the paper, we also attempt to point to the significant, growing, and inspired literature about state APCDs, which itself may be valuable to readers.

While this paper proposes a pathway toward a more efficient and effective state and national system of health system data collection and use, it does not have a monopoly on good or viable solutions. It does, however, seek to establish a common understanding of a national health data need and set a common horizon to focus our collective attention and efforts on behalf of Americans who pay for, and immeasurably benefit from, our health care system.

## II. State APCD Landscape

State APCDs have proliferated since they were first established in the early 2000s. Eighteen states presently operate an APCD, with another eight states actively developing or seriously considering establishment in the coming years. APCDs are large and complex health data repositories, comprising tens of millions of records of health care services provided to millions of individuals across public and private coverage types. When properly curated and resourced, APCDs are capable of supporting policymakers, regulators, researchers, purchasers, and consumer advocates in better understanding the performance of our systems of health, the changing health of our populations, and the drivers of health care cost growth.

### A. What Are State APCDs?

State APCDs are large and complex repositories of health care claims and encounter<sup>iii</sup> data for individuals receiving health insurance through most public and private sources. State APCD data is collected directly from payers licensed to operate in local markets, including state Medicaid agencies, commercial health plans, and TPAs, with collection often extending to pharmacy benefit managers (PBMs), behavioral health benefit managers, and dental plans.

#### Health Care Claims 101

Claims and encounter data include information on individuals' diagnoses, the services and prescriptions they receive, the providers delivering the services, and the amounts paid for the services or goods by the payer and by the individual, in accordance with plan cost-sharing requirements and to the extent populated by the payer.<sup>21</sup> State APCDs vary in whether they collect denied claims.

The data state APCDs collect from payers also comprise important contextual information for payment data, including:

- Individual and population characteristics (e.g., gender, age, ZIP code) in member eligibility files;<sup>22</sup>
- Plan characteristic information (e.g., product type, name, premium) in plan files;<sup>23</sup> and
- Provider information (e.g., provider type, provider location) in provider files.<sup>24</sup>

Together, these APCD files—collected monthly, quarterly, or annually, depending on the state—may be linked and supplemented with analytically important information (e.g., diagnosis groupers, master person indexes, master provider indexes) to support state data analytics and use.

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<sup>iii</sup> Encounters are records of services delivered that may not be tied directly to a payment amount. As more payers and providers are covered under non-fee-for-service (FFS), alternative payment arrangements, more of the “claims” that APCDs receive are encounters, resulting in a greater loss of payment field integrity.

### **Administrative Data: Operational Records That Evolved Into Strategic Data Assets**

In 1996, as part of the Health Insurance Portability and Accountability Act (HIPAA), Congress required those seeking payment from federal programs to bill electronically using uniform coding standards, allowing for greater payment automation and analytics to identify fraud, waste, and abuse.<sup>25</sup> However, as many early APCD states learned, federal claims—or “administrative data”—standards did not cover all fields users require for population health or health system research, and payer practices for how they maintain non-standardized fields (or files) vary considerably. Payer data variation placed—and still places—considerable burden on prospective users, like APCD agencies, to normalize data for analytic use, often limiting data utility (see Section IV.3).

However, as federal, state, and industry expectations have grown with respect to how payers and providers are expected to use information embedded in these administrative data (e.g., to better manage and coordinate the care, improve operational and network efficiency, control costs, report on service quality and outcomes) so too has the level of data standardization, and the completeness, richness, and utility of this data for supporting research. The national data ecosystem has also evolved to support new administrative data uses.

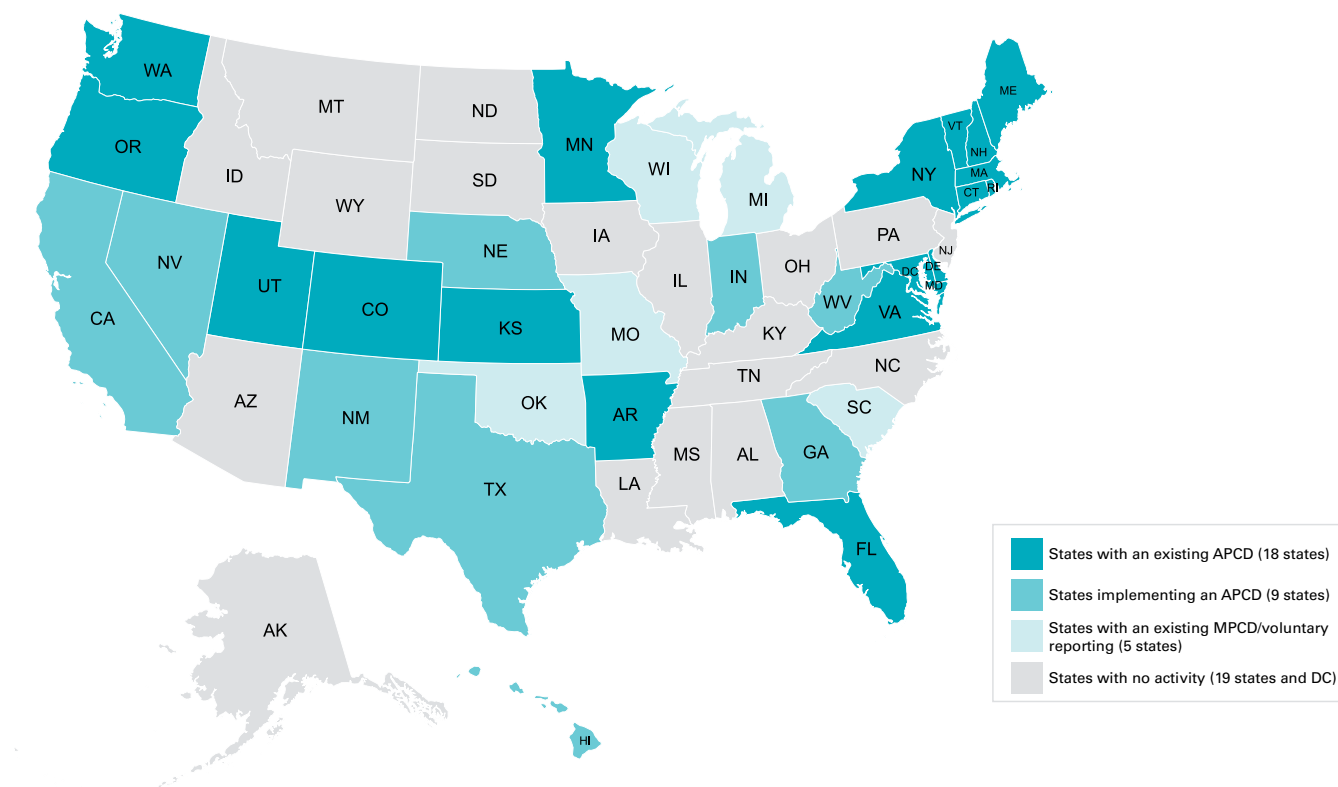
- Designated Standards Maintenance Organizations (DSMOs) have expanded claims format, transaction and coding standards to accommodate:
  - The recording of more detailed clinical and non-clinical information about patient health (e.g., expanded International Classification of Diseases, 10th edition (ICD-10) code set, including new social determinants of health (SDOH) Z-codes) and service utilization (e.g., expanded use of modifiers); and
  - More efficient transaction methods to share greater volumes of data faster (e.g., fast healthcare information resources (FHIR) application program interfaces (APIs)).
- Public and private payers—particularly Medicare and Medicaid—have higher expectations for the completeness and accuracy of the administrative data they receive, developing and implementing stronger incentives and penalties for stronger downstream/provider coding.
- Federal and state governments and payers and providers are investing more heavily than ever in health information technology (HIT) and analytic infrastructure in order to derive meaningful information from the data they collect, integrate, and receive to support their role as a purchaser or provider of health care.

Claims and encounter data are now a cornerstone asset of almost every payer’s and provider’s cross-market competitiveness strategies and an increasingly valuable public data resource, collected, curated, and analyzed by state APCDs nationally.

## APCD States

As of June 2022, 18 states have operating APCDs, with another eight states—California, Georgia, Indiana, Missouri, Nevada, New Mexico, Texas, and West Virginia<sup>26</sup>—actively developing or seriously considering APCD establishment. Several states, including Nevada, have legislative mandates to create an APCD, dependent on the release of federal Consolidated Appropriations Act (CAA) APCD grant funding (see Section III.E).<sup>27</sup>

**Exhibit 4: State APCD State of Play (September 2022)**<sup>28</sup>



State APCDs may be stewarded by various state departments, including:

- Health departments (e.g., Minnesota, Utah);
- Health data and/or policy departments (e.g., California, Connecticut);
- Insurance departments (e.g., New Hampshire,<sup>29</sup> Arkansas<sup>30</sup>); or as
- Their own programs within broader health and human services agencies (e.g., Florida, Oregon).

State APCDs may also be located within quasi-governmental<sup>31</sup> agencies (e.g., Massachusetts CHIA, MHDO), or within independent non-profits contracted or funded to operate on behalf of the state (e.g., Colorado’s CIVHC, VHI). States are increasingly co-locating health data resources to create versatile **state HDOs** capable of cross-data set integration that have diversified revenue sources and scale to support scaled analytic and data privacy teams.

The [NAHDO](#) and the [APCD Council](#), a joint program between NAHDO and the University of New Hampshire, serve as national convening organizations for state HDOs—including those that steward APCDs—nationally, supporting knowledge-sharing, networking, and data collection alignment.

### Additional Resources

For more information about individual state APCDs, see the:

- [APCD Council’s Interactive State Report Map and inventory of APCD characteristics](#);<sup>32</sup> and
- [Employers’ Forum of Indiana’s APCD overview for employers and other health care purchasers](#).<sup>33</sup>

For more information about state APCDs operations, see the:

- Foundational “Basics of All-Payer Claims Databases” primer—and the more recent “The ABCs of APCDs”—written by the APCD Council co-chair, Jo Porter, and the indomitable Denise Love;<sup>34</sup>
- Commonwealth Fund series on APCDs—particularly “Part 1”—authored by Doug McCarthy;<sup>35</sup>
- Environmental scan and analysis conducted by Freedman HealthCare to inform the design of California’s Health Care Payments Data Program;<sup>36</sup> and
- “APCD Development Manual and Model APCD Legislative Language” developed by the APCD Council with support from the Gary and Mary West Health Policy Center.<sup>37</sup>

### Other Public and Private Claims Databases

Stakeholders may access other payer administrative datasets not discussed in this paper, but which may be used to support similar use cases, including the following:

**State and Regional Multi-Payer Claims Databases (MPCDs)**, such as those stewarded by the [Wisconsin Health Information Organization](#) (WHIO) or the [Midwest Health Initiative](#) (MHI), depend upon voluntary payer claims submissions to derive user value. WHIO’s MPCD, for example, reports to have data for nearly 75% of the state’s population (higher than most state APCDs).<sup>38</sup> WHIO uses this data to support public reporting (e.g., tracking primary care quality, identifying populations at risk for serious COVID-19 infections) in addition to private use cases.<sup>39</sup> WHIO and MHI are sustained through private contracts with submitters and other users.

**Health Information Exchanges (HIEs)**, such as California’s [Manifest MedEx \(MX\)](#), are increasingly using claims data from participating payers to integrate with and derive new value from their clinical data.<sup>40</sup> In a 2019 survey by the eHealth Initiative and Orion Health:

- 24% of HIEs with payer participants reported having access to claims data for more than three million members (13 organizations);
- Most larger HIEs reported capabilities to integrate clinical and claims data; and
- 20% of responding HIEs were planning to “adopt” an APCD-like model in the coming years.<sup>41</sup>

The Delaware Health Information Network (DHIN) established its own APCD in 2017, which it plans to pair with its HIE data to create a complete longitudinal record, allowing payers to better measure provider organization performance.<sup>42</sup>

HIEs are increasingly seeking to serve as regional “health data utilities”—a model effectively championed by [Civitas Networks for Health](#)—building local capacity to integrate clinical, claims (from APCDs and directly from payers), public health, and other data to support the health information needs of the public and private sectors.<sup>43</sup>

**Private MPCDs**, such as those stewarded by the [Health Care Cost Institute \(HCCI\)](#), [FAIR Health](#), [Merative \(Previously IBM MarketScan\)](#), [Optum](#), and [Clarify Health](#) and joined by myriad private claims data aggregators and vendors, offer users more analytic-ready data with broader, cross-state populations than individual state APCDs. However, the utility of private claims databases may be limited by their:

- Breadth of data, as vendors may only have data for national payers, limiting use cases for markets with greater local payer penetration or data only for specific lines of business;
- Depth of data, as vendors may not have access to certain member, plan, service, and provider information;
- Cost, as vendors seek returns on their data assets based on the value to the potential user;<sup>44</sup> and
- Use restrictions stipulated by the contractual terms the vendor has with its data suppliers to avoid the investigations that may be averse to the data supplier’s interests.

Many private claims databases report to comprise health data for hundreds of millions of Americans, ready for use by private enterprises to make strategic business decisions and researchers to support investigations. One product, for example, purports to comprise “de-identified, patient-level health data for over 273 million US lives reflecting the continuum of care,” allowing users to derive valuable information about health care markets and the consumers who rely upon it.<sup>45</sup> The company stewarding this data resource was sold for a reported \$1 billion in January 2022.<sup>46</sup>

While many for-profit private claims databases can provide users with broad and efficient insights into health system performance, their vendors choose with whom to share data, to what extent, for what purpose, and at what cost. Vendors may choose not to have a set data fee schedule, and instead, base costs on the perceived value of the use case to

While many for-profit private claims databases can provide users with broad and efficient insights into health system performance, their vendors choose with whom to share data, to what extent, for what purpose, and at what cost.

the prospective user, with discretion and authority to deny the sale. Private claims databases are also typically subject to fewer oversight requirements than public data resources like state APCDs, though new regulations in light of recent Supreme Court decisions may be forthcoming.<sup>47</sup> Congress is currently deliberating an omnibus consumer data privacy bill, the American Data Privacy and Protection Act.<sup>48</sup> Private claims databases may be subject to additional oversight if they are a CMS-certified Qualified Entity (QE) and receive Medicare claims data.

## B. Which Populations Are Included in State APCDs?

State APCDs typically have data for up to two-thirds of state residents across public and private coverage types (Exhibit 5). Data for approximately 64 million individuals are presently included in state APCDs, with that number set to nearly double to 120 million individuals—or 37% of the total U.S. population—once in-development APCDs are operational.<sup>49</sup>

**Exhibit 5: Data Typically Included in State APCDs by Plan Type**

	Generally Included	Sometimes Included	Rarely Included (Due to Federal Restrictions)
Medical Insurance Line of Business	<ul style="list-style-type: none"> <li>Individual market plans, including ACA Marketplace plans</li> <li>Small- and large-group (fully insured) plans</li> <li>Medicaid FFS and managed care plans</li> <li>Medicare Advantage plans</li> <li>State and local employee health benefit plans (fully <b>and</b> self-insured)</li> </ul>	<ul style="list-style-type: none"> <li>Medicare FFS payer data</li> <li>Medicare Part D (prescription drug) plans</li> <li>Dental plans</li> </ul>	<ul style="list-style-type: none"> <li>ERISA-preempted, self-insured plans</li> <li>Federal Employee Health Benefit (FEHB) Program Plans</li> <li>Veterans Health Administration (VHA) plans</li> <li>Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA) plans</li> <li>TRICARE plans</li> <li>Indian Health Service (IHS) information</li> </ul>

### Covered Populations

Most state APCDs have data for individuals with insurance regulated by the state. This includes data for individuals administered by state programs, such as Medicaid, ACA Marketplace plans, and state and local employee health benefit plans, as well as plans regulated by local departments of insurance, such as small- and large-group fully insured plans. State APCDs also typically receive Medicare Advantage plan data—and even Part D data—as part of commercial payers’ submissions.



### CMS QEs

State APCD agencies may also seek certification by CMS to receive Medicare Part A, B, and D claims data for use in evaluating provider performance. CMS QEs are required to use the Medicare data they receive to produce CMS-approved reports on provider performance, but may also use the data to support non-public analyses and resell it to certain authorized users. There are currently 36 certified QEs nationally, including the following state APCD and MPCD organizations: CIVHC; MHI; MDH, Division of Health Policy; VHI; and WHIO. Several organizations that steward private MPCDs are also certified QEs and must abide by CMS rules in the use of Medicare claims data they receive, including Clarify Health Solutions, FAIR Health, HCCI, Komodo Health, and OptumLabs.

### Excluded Populations

State APCDs have limitations in their data collection authorities, which result in notable data gaps.<sup>50</sup>

Since the Supreme Court's 2016 decision in *Gobeille v. Liberty Mutual Insurance Company*, state APCD agencies are not allowed to require the submission of claims data for individuals covered by **ERISA-preempted self-insured plans**, which cover over a quarter of Americans.<sup>51,52</sup> States may require self-insured state and local government employee benefit plans to submit data to APCDs and request voluntary data submissions from self-insured employers, which can mitigate data gaps.<sup>53</sup> For more information about the history of state attempts to regain access to this data and the implications of self-insured data losses to state APCDs, see Section [IV.2.1](#).

State APCDs rarely have data for individuals receiving coverage or care through **federally administered programs**, including the: FEHB Program plans, VHA, the CHAMPVA, TRICARE, and the IHS. While state APCD agencies may receive Medicare FFS (i.e., Parts A and/or B) membership and claims data from CMS if they are certified as a QE, integration and use of Medicare FFS data remain limited.

State APCDs do not—and will not—contain information on services rendered to individuals who are **uninsured** or who pay for health care services wholly out-of-pocket ("**self-pay**"). Claims records for self-pay or charity care services are not shared with payers, and are therefore not available for payers to share with a state APCD. This limitation will exist regardless of the state APCD operating model. States may, however, pair APCD data and hospital discharge data to estimate the extent of this data gap.<sup>54</sup>

## C. How Are State APCDs Used?

State APCDs offer policymakers, regulators, researchers, purchasers, and consumer advocates a unique tool to better understand how our systems of health are performing to inform their policy, program, and purchasing decisions. APCDs allow person-, provider-, and service-level analyses at a point in time or over time, offering insight into how policy, program, and public health changes may impact health care coverage, utilization, costs, and outcomes. State APCDs have been or may be used to:

- Create and monitor baseline statistics of population health care coverage, service utilization, costs (including by priority service types, such as primary care and behavioral health care), and health outcomes, and identify how measures have changed over time.<sup>55</sup>
- Identify where health service inequities and health disparities exist among populations to direct and shape policy and program interventions.<sup>56</sup>
- Support regulatory and program oversight of payers and providers, from compliance with network adequacy requirements to market consolidation impact assessments.<sup>57</sup>
- Identify health system failures—including excessive cost growth or price variation, preventable ED visits, and irregular billing practices—to inform policy and program responses.<sup>58</sup>
- Facilitate an understanding of whole person health needs by linking cross-plan data for an individual (e.g., dual-eligible analyses) or cross-sector data sources (e.g., COVID-19 long-haul analyses, opioid disorder prevalence).<sup>59</sup>
- Provide purchasers, payers, providers, and consumers with health service price and quality information to inform purchasing and care delivery decisions, including to mediate out-of-network payment disputes between payers and providers.<sup>60,61</sup>
- Provide health care payers and providers with data on community health needs.<sup>62</sup>
- Develop public and private payer cost estimates for reforming programs, designing new value-based purchasing arrangements, or adding new coverage benefits.<sup>63</sup>

How states use their APCDs—or the “use cases” they pursue—often varies by the priorities of the department or entity within which the APCD is housed, the priorities of the stakeholders that fund it, and the limitations of its use per local regulation. For example, among the states that presently operate an APCD, these resources have been used by:

- **Arkansas** to support a federally funded study assessing medical marijuana’s societal impact;<sup>64</sup>
- **Colorado** to understand health care spending drivers, including the prevalence of low-value care;<sup>65</sup>
- **Connecticut** to inform cross-payer measures of health outcomes and costs;<sup>66</sup>
- **Delaware** to monitor statewide opioid prescriptions and ED visits;<sup>67</sup>
- **Maine** to identify the state’s costliest drugs and track their prescription patterns at retail and mail-order pharmacies;<sup>68</sup>
- **Massachusetts** to monitor health insurance enrollment trends over time and across payers;<sup>69</sup>
- **Minnesota** to understand chronic condition prevalence and medication nonadherence;<sup>70</sup>

- **New Hampshire** to assess regulated plans' network adequacy standards;<sup>71</sup>
- **Oregon** to identify primary care spending trends and inform policies seeking to increase investments in such services;<sup>72</sup>
- **Rhode Island** to track ED follow-up rates for mental health and substance use disorder (SUD) visits;<sup>73</sup>
- **Utah** to assess provider payment variation for shoppable services;<sup>74</sup> and
- **Virginia** to create a Commercially Reasonable Payments Dataset to help resolve payment disputes for out-of-network services.<sup>75</sup>

State APCDs may also serve as data “backbones” for multi-departmental and multi-dataset analyses, where individual identifiers may be used to link siloed records to derive new insights. For example, the Oregon Health Authority (OHA) has linked death record data to its APCD, the All Payer All Claims (APAC) database, to support health outcomes research.<sup>76</sup> Massachusetts' CHIA has used the MA APCD as the data “spine” to support a legislatively required assessment of “fatal and nonfatal opioid overdoses in Massachusetts.”<sup>77</sup> CHIA's analysis implicated 22 datasets from nine state departments and multiple community-level data sources to derive its results. Data from Vermont's APCD, VHCURES, was similarly integrated with the state's cancer registry data to study trends in lung cancer screening, incidence, and outcomes.<sup>78</sup>

State APCDs may also serve as data “backbones” for multi-departmental and multi-dataset analyses, where individual identifiers may be used to link siloed records to derive new insights.

State APCDs may be used to produce indicators and other contextual information that may unlock value in other data sets. For example, through the Arkansas Healthcare Transparency Initiative, ACHI, steward of the Arkansas APCD, has used APCD to support other analyses of hospital discharge data, ED data, birth and death record data, disease registry data, county jail booking data, and medical marijuana cardholder and dispensary data.<sup>79</sup> Integrated data have been used to support numerous investigations, including investigations of root causes for infants who died within the first 12 months of life and assessments of health care utilization and jail involvement changes for individuals who were seen in crisis stabilization units.<sup>80</sup>

There is also an increasing volume of cross-state APCD use cases and publications. Prominent recent examples of coordinated, multi-state APCD analyses include the:

- New England States Consortium Systems Organization's (NESCO) analysis, conducted by Onpoint Health, to understand cross-state and line-of-business primary care spending differences;<sup>81</sup>
- Robert Wood Johnson Foundation (RWJF)-funded Network for Regional Healthcare Improvement (NRHI)-coordinated effort to produce total cost of care measures across five states;<sup>82</sup> and
- RAND Corporation's ongoing work assessing cross-state and line-of-business provider price variation.<sup>83</sup>

Other researchers have also demonstrated that cross-state APCD analytics are currently possible, but require tight cross-state coordination, narrow use cases, and—as discussed in Section IV.3—investments of time and resources to acquire and harmonize data.<sup>84</sup>

State APCD use and utility vary significantly across states. Not all established state APCDs are high-performing data resources. The most productive state APCDs are those with agencies that directly engage stakeholders to identify their most pressing data needs, seek and acquire reliable funding to support the data use cases, and continually ensure results are delivering expected value.

### **Additional Resources**

For additional information about state APCD use cases and their impact on policymaking and markets, see our related work<sup>85</sup> and other resources including the:

- *APCD Showcase*, a website managed by the APCD Council;<sup>86</sup>
- Commonwealth Fund series on APCDs authored by Doug McCarthy;<sup>87</sup>
- Comprehensive reporting by RAND Health to support the State All Payer Claims Database Advisory Committee (SAPCDAC) and the Office of the Assistant Secretary for Planning and Evaluation (ASPE);<sup>88</sup>
- Work from Freedman HealthCare, and Issues Research, NAHDO, and StratCommRx, assessing the feasibility of establishing an APCD in Alaska and Missouri, respectively;<sup>89</sup> and
- APCD overview by Lynn Blewett and the State Health Access Data Assistance Center (SHADAC) in the *Journal of Health Politics, Policy, and Law*.<sup>90</sup>

## III. State APCD Operations

The state APCD operating model broadly includes four main activities: data collection from national and local payers licensed to operate in state markets, data curation and normalization to support internal and external analytics and use, data reporting based on internal analytics, and data release to support external analytics. State APCD agencies support these activities by investing in data and analytic infrastructure, protected and secure data environments and processes, stakeholder relationships, and capable data, analytic, and legal staff. State APCD agencies frequently contract with vendors to maintain these activities and the foundational infrastructure required to support them. State APCD agencies depend heavily on state General Fund support, though many are offsetting at least part of their expenditures with federal Medicaid matching funds, philanthropic dollars, and revenue from data licensing. The federal government has historically provided several opportunities for states to invest in their local health data infrastructure, including APCDs, though its direct engagement in APCD policymaking has been largely limited to date.

### A. State APCD Operating Model

The state APCD operating model broadly comprises four main activities:

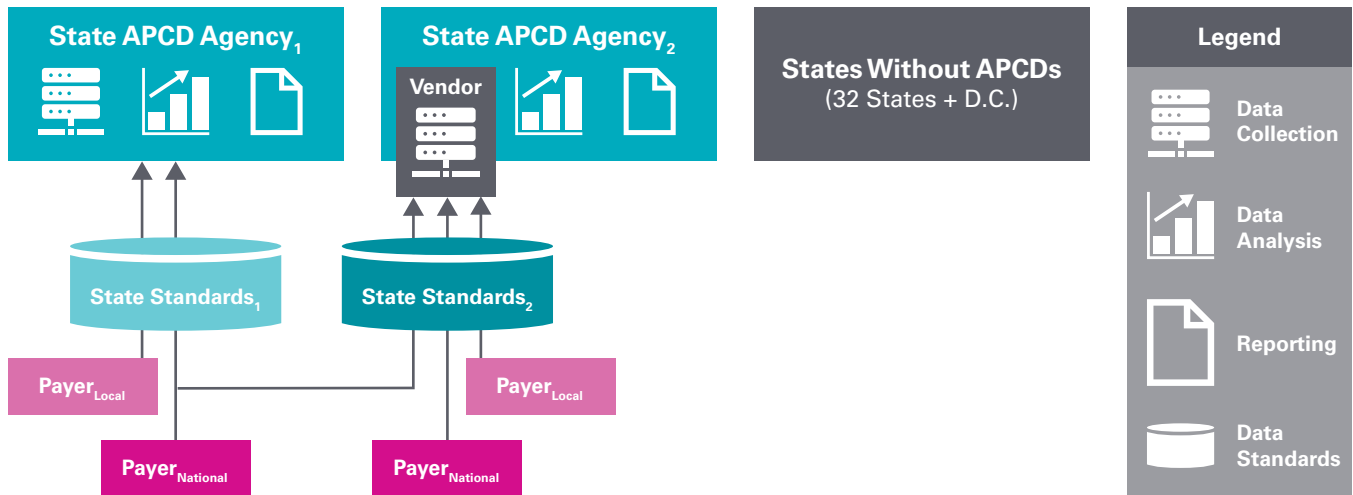
1. Data collection from national and local payers licensed to operate in state markets using individual state data file, field, and format standards;
2. Data curation and normalization to support analytics, which may include steps to de-identify data to further protect consumer privacy or add data fields to support analytic utility;
3. Data reporting based on internal analytics, which can result in a spectrum of use cases (as previously discussed); and
4. Data release to support external use, if release is permitted by state law.

Each of these activities is undertaken in accordance with federal and state data privacy requirements, as discussed more extensively in the next section (see Section III.B).

#### 1. Data Collection

In the current APCD operating model ([Exhibit 6](#)), payers and TPAs licensed to do business in a state may be required to submit health care membership and claims data to the state's APCD. Payer submissions are required to align with the state's APCD data collection standards, practices, and processes. Submission requirements can comprise five to nine different files,<sup>91</sup> with submission frequencies varying (e.g., monthly, quarterly, and annually) by state and file type.<sup>92</sup> State submission standards for files vary, though they often share a common "core" of fields and field definitions, as documented in the APCD Common Data Layout (CDL) and are maintained by NAHDO and the APCD Council (see call out).

**Exhibit 6: Current State APCD Operating Model**



Payers are typically required to submit data for members, member services, and servicing-providers across most lines of business, including individual/ACA Marketplace plans, fully insured plans, Medicare Advantage and Part D plans, and state employee benefit plans (fully or self-insured), with the notable exception of self-insured employer-sponsored plans subject to ERISA, where data submission is voluntary (as previously discussed and discussed further in Section IV.2.1).

### The APCD CDL

After the 2016 *Gobeille* decision, in an effort to develop a common data standard and preserve APCD agencies' self-insured data collection, NAHDO, the APCD Council, and the NASHP worked with states and payers to develop the APCD-CDL, which offers common technical specifications for APCD file structure, format, and fields.<sup>93,94</sup> The APCD-CDL is maintained by the APCD Council and volunteers from state APCD agencies and other stakeholders. The APCD-CDL was submitted to but never approved by the DOL as a standard by which states could request self-insured data from payers and TPAs; the SAPCDAC recently renewed calls for U.S. Department of Labor (DOL) approval.

Few existing state APCD agencies have modified their data submission guides to match the APCD-CDL, a likely byproduct of financial barriers to making such changes and a lack of incentive to do so. VHI is among the few state APCD agencies that have altered their data collection specifications to match the APCD-CDL, though several others—including Colorado's CIVHC—have recently taken steps to strengthen alignment.

New APCD states almost universally use the APCD-CDL as the foundation for their data submission guides. California, for example, has adopted the APCD-CDL without modification and plans to participate in the APCD-CDL Maintenance Committee to recommend modifications as needed. Other emerging APCD states like Texas have used the APCD-CDL as the starting template on which they plan to build.<sup>95</sup> While the use of the APCD-CDL by new APCD states is helpful in minimizing future state-by-state data specification variation, variation will likely persist without shared governance to maintain a common, required data standard.

The universe of payers required to report to an APCD varies by state and can expand beyond “traditional” insurance carriers to include TPAs and PBMs that are licensed by the state. Payers required to report include those that meet local “covered lives” or annual premium thresholds, as set by each state in relation to state population. For example, in New Hampshire, with a population of just under 1.4 million individuals, payers must submit data to the state’s APCD, the Comprehensive Health Care Information System (CHIS), if they cover at least 10,000 state residents.<sup>96,97</sup> Meanwhile, in California, with a population in excess of 39 million individuals, the payer submission threshold for data submission to its in-development APCD, the Health Care Payments Data (HPD), is four times that at 40,000 state residents.<sup>98</sup>

State Medicaid programs typically submit data directly to state APCDs for individuals not covered under managed care (i.e., FFS), often in alignment with modified specifications that reflect Medicaid’s unique design and data.<sup>99</sup> For example, Massachusetts’ CHIA, steward of the MA APCD, requests a distinct Member Eligibility File from MassHealth, the state’s Medicaid program, to ensure important Medicaid data fields are captured.<sup>100</sup> CHIA’s MassHealth Enhanced Eligibility (MHEE) File captures both member eligibility and enrollment information, a distinction that is generally not needed for private commercial plans but is essential for understanding an individual’s Medicaid benefits.

Several state APCD agencies that have been certified as QEs also receive Medicare FFS (i.e., Parts A and/or B) data from CMS for integration into their APCDs, though integration rates remain low.<sup>101</sup>

## 2. Data Curation and Normalization

State APCD agencies conduct quality edits—many automated at submission—on the data they receive from public and private payers to support quality assurance and, ultimately, data normalization in preparation for analysis. The types of edits and the thresholds for passage vary across state APCDs. Quality assurance processes are typically most rigorous on files and fields that are most frequently used by the agency and are informed by the local market knowledge of payers, products, and providers. As described by West Health’s “All-Payer Claims Database Development Manual,” developed in partnership with the APCD Council:

Important core controls include data edits, error thresholds, and benchmarking. As data are submitted, field-level and quality edits are detected, ensuring that the data elements are populated, and the values of the data elements fall within reasonable limits. Over time, [payer]-specific thresholds are often established... after the state and the carrier review historical data...to determine if there are unique characteristics that require [payer]-specific thresholds.<sup>102</sup>

Quality assurance checks can include:

- Reviews of claims ratios and volumes across payers, lines-of-business, service lines, and populations, and for payer submissions over time;
- Frequency distributions of values and field lengths;
- Calculations of per member per month claim volumes and costs by payers, line of business, and service lines in aggregate and by individuals;
- Review of claim submission duplication across payers (e.g., medical insurer and PBM) using master member identifiers; and
- Eligibility span tests to ensure payer submission consistency.<sup>103</sup>

States APCD agencies may “de-identify” data in-house or before payer data is even received (i.e., de-identification by the payer or by a contracted third-party data intermediary) to protect patient privacy in alignment with federal or state requirements or voluntary state agency practices (see Section III.B).

### 3. Data Reporting

State APCD agencies maintain internal and contracted analytic teams to support local reporting, which can vary significantly across states in focus and volume (see Section II.C). Analytic teams are often expected to have health care claims and policy knowledge as well as the technical skills required to analyze large and complex data sets in tools such as SAS, STATA, or R, to support meaningful and contextualized analyses. Analytic teams typically have access to only a subset of the data submitted to the state APCD, providing another layer of patient privacy protection.

### 4. Data Release

State APCD agencies may allow for normalized, “analytic ready” data to be released to external users based on each state’s data access requirements. If permitted by state law, state APCD agencies have distinct processes—often including both legal and data use case reviews—for determining whether external data access is allowed, and if so, for which entities, for what purposes, to what extent, and at what cost. For a more detailed description of state release restrictions and protocols, see Section III.B.

Depending upon local regulations, state APCD agencies may sell APCD data extracts, with data fees varying by data set and user type, as outlined in public or “upon request” fee schedules. Most integrated (i.e., linked membership and claims data), single-year state APCD data sets can be acquired for between \$10,000 and \$20,000, with additional data curation and analytic support often available from the agency for an additional fee. Example APCD data acquisition fees are shown in Exhibit 7.

**Exhibit 7: State APCD Data Fees (Sample)<sup>iv</sup>**

State APCD	Data Set Type			Cost Range
	Individual Data Files	Integrated Data Sets	License for Data Access	
Arkansas APCD <sup>104</sup>		X		\$11,000+
Colorado APCD <sup>105</sup>		X		\$13,500+
Connecticut APCD <sup>106</sup>	X			\$1,000-\$4,000
Delaware APCD (Health Care Claims Database) <sup>107</sup>			X	\$15,000+
Massachusetts APCD <sup>108</sup>	X			\$2,500
Maryland APCD (Medical Care Data Base) <sup>109</sup>	X			\$3,000
Maine APCD <sup>110</sup>	X			\$1,400-\$4,000
Oregon APCD (All Payer All Claims) <sup>111</sup>		X		\$890 + Staff time
Rhode Island APCD <sup>112</sup>			X	\$25,000
Utah APCD <sup>113</sup>		X		\$10,000+

<sup>iv</sup> Assessment of publicly available information. Please contact states for latest data access conditions, file acquisition options, and rate information.



## B. State APCDs: Balancing Data Privacy and Data Utility

In establishing an APCD, each state sets its own balance between prohibiting access to the person-level health data they steward (data privacy) and ensuring that prospective users have access to enough data to support their use cases (data utility).<sup>114</sup> States strike this balance by establishing regulations and rules to govern what data state APCDs may collect (data collection); how state APCD data, once collected, must be managed, including who can access and use the data internally (data management, access, and use); and for what purposes, under what circumstances, and in what form state APCD data may be released (data release). The earlier in this process that states introduce data restrictions or protections, the lower the risk of unintended disclosures, but also the greater the loss of data utility. States often set these restrictions in alignment with—and building from—federal health data privacy laws and industry best practices for handling and use of protected health information (PHI).

### Exhibit 8: States and State APCD Agencies Can Set Rules and Procedures to Safeguard Data Privacy at Various Stages



### State APCDs and HIPAA

State APCDs are typically not HIPAA covered entities and therefore are not directly subject to HIPAA.<sup>115</sup> However, most state APCD agencies follow many of HIPAA’s privacy and security provisions,<sup>116</sup> which provide baseline safeguards for PHI and ensure “consistent management of claims data and PHI among stakeholders and data submitters.”<sup>117</sup>

#### HIPAA 101

HIPAA was established to provide national standards for electronic health care transactions and minimum standards for the privacy and security of PHI.<sup>118</sup> The Department of Health and Human Services (HHS) implemented HIPAA through its adoption of the Privacy Rule, which defined how PHI may be used and disclosed, and the Security Rule, which established PHI security standards.<sup>119</sup> HIPAA requirements apply to “covered entities”—health plans, health care clearinghouses, and health care providers engaged in the electronic exchange of health care transactions—and aim to “protect the privacy and security of individuals’ medical records and other individually identifiable health information maintained or transmitted by or on behalf of [these] entities.”<sup>120</sup>

Given that state APCDs often are not subject to HIPAA, payers have raised concerns about sharing PHI—particularly voluntarily sharing ERISA-preempted self-insured PHI—with them, suggesting that state APCD agencies consider abiding by “minimum necessary data standards” when collecting data and “use third-party vendors to de-identify” collected data prior to agency receipt.<sup>121</sup> States have pushed back on the suggestion.

Minnesota notes that “HIPAA permits disclosure of [PHI] without patient consent by a covered entity ... [including] to a public health authority, such as the Minnesota Department of Health [which stewards the state’s APCD] (45 CFR § 164.512(b)).”<sup>122</sup> Further, while de-identification methods exist that would preserve state APCD agencies’ ability to support longitudinal analyses, de-identification prior to intake would also likely require the “removal of many data elements that may be indirect identifiers (like zip code or age), seriously limiting [APCDs’ analytic] capabilities.”<sup>123</sup> A brief from the University of New Hampshire, the APCD Council, NAHDO, and NASHP pressed further:

Some data submitters have expressed concern that if state law cannot compel the submission of claims data from self-funded employer sponsored plans, submitting such data might raise privacy concerns, specifically under HIPAA privacy regulations. According to legal scholars, claims data voluntarily submitted by self-funded ERISA plans would continue to comply with HIPAA privacy requirements notwithstanding the Gobeille decision. ...The HIPAA Privacy Rule permits health plans, including self-funded ERISA plans, to disclose identifiable claims data without individual authorization where required by law or authorized by law for health oversight or public health activities. Even if not mandated by law, self-funded ERISA plans and their TPAs are allowed to submit data voluntarily to APCDs under the HIPAA Privacy Rule.<sup>124</sup>

Adjudication of this issue is beyond the scope of this paper and the knowledge of its author; for additional expert considerations on HIPAA, HIPAA’s implications for state APCDs, and key state APCD considerations for protecting data privacy while maximizing data utility, readers should see the:

- SAPCDAC Report’s detailed discussion on “The HIPAA Rules and APCDs” and “Data Privacy, Security, and Release”;<sup>125</sup> and
- The Source on Healthcare Price and Competition’s data privacy and governance state case examples and data privacy recommendations for California as it considered establishing its own APCD.<sup>126</sup>

### **The Impact of Dobbs on Individual Health Data Privacy and State APCDs**

On June 24, 2022, the Supreme Court, in its review of *Dobbs v. Jackson Women’s Health Organization*, ruled that the U.S. Constitution did not protect the right to abortion and deferred the matter to states.<sup>127</sup> Rescinding this long-standing right had immediate and life-altering implications for women nationally. The decision elevated a new patchwork of state laws by which women’s reproductive decisions would be governed, including potential criminal penalties for women and their doctors. The Dobbs ruling also creates new risks for patient-provider confidentiality and how an individual’s personal health data may be weaponized in states where abortion is outlawed.<sup>128</sup> While HHS and its Office of Civil Rights (OCR) responded to the ruling by providing additional information on how the HIPAA Privacy Rule protects individuals’ PHI, its protections have limits to their authority (e.g., where state law explicitly requires reporting by statute or with presentation of a subpoena, warrant, or court order) and do not apply to non-HIPAA covered entities, which, as discussed, includes state APCDs.<sup>129</sup> As the Administration<sup>130</sup> and federal<sup>131</sup> and state<sup>132</sup> legislatures across the country draft and consider new consumer health data privacy protections, **state APCD agencies should assess their governing data privacy protections and, where necessary, identify opportunities to strengthen regulations to ensure that the health data they collect may not be used for unintended purposes.**

### **Protecting Data Privacy: Data Collection**

In 2019, the CedarBridge Group conducted a national APCD data privacy and security environmental scan and found that one in five state APCDs do not collect and store PHI for analytic use. State decisions to limit their scope of data intake structurally minimizes subsequent data privacy risks, but also structurally limits their ability to “integrate claims data with data from other sources, impacting the overall value of the APCD program.”<sup>133</sup> State APCD data collection approaches vary significantly.<sup>134</sup>



Minnesota’s APCD agency, the MDH, is one of the agencies limited by state law in what data it may collect. The MDH does not collect raw personally identifiable information (PII) from data submitters (payers). Instead, for fields like Social Security number, name, and address, it requests that payers submit encrypted values using a common methodology, preventing re-identification while preserving “the ability to trace care across payers and delivery system settings.” While this approach has presented “significant challenges[,] ... new technology and statistical techniques have helped [DOH to] accomplish [linking] in a vast majority of [use] cases.”<sup>135</sup>

Other states have voluntarily chosen to limit the data they receive to minimize data privacy risks. Massachusetts' APCD agency, CHIA, developed and implemented a tailored strategy that would "dramatically decrease the risk of exposure of collected PII while retaining the ability to connect data," preserving data utility.<sup>136</sup> Its solution, developed in partnership with Onpoint Health, included:

- Deploying software to data submitters (payers) that: replaces key PII fields with pseudonymized equivalents, drops certain data field values where not applicable to Massachusetts, and encrypts data files with National Institute of Standards and Technology (NIST)-compliant encryption before transmitting to CHIA;
- Sunsetting the collection of certain fields (e.g., select PII on health care claim records); and
- Storing raw data separately from that in the analytic data warehouse (which has broader user access) and not allowing access to raw data by internal or external data users.

States and state APCD agencies may also choose to exercise their APCD data collection authorities to varying extents to minimize or maximize the data they receive. Massachusetts and Utah illustrate the spectrum of exercised state data collection authorities for various populations ([Exhibit 9](#)).<sup>137</sup> Massachusetts' APCD comprises data for individuals covered by health plans contracted in the commonwealth (regardless of whether the individuals on those plans live inside or outside Massachusetts), as well as those residing in the Commonwealth (regardless of where the state members' plans are contracted).<sup>138</sup> Utah, conversely, limits its data collection to individuals covered by health plans contracted in the state, and then only to plan members residing in the state.<sup>139</sup> Neither state receives data for individuals who may be served by state health care entities but who reside out of state or are not covered through a state-based contract.

**Exhibit 9: APCD Plan and Member Data Collection Requirements (For Illustrative Purposes)**

Massachusetts				Utah			
	State Resident				State Resident		
		Yes	No			Yes	No
Covered Under State-Regulated Contract (Sitused)	Yes			Yes			
	No			No			

The scope of a state APCD's data collection can open or limit its capabilities to support regional, and insurance or provider-focused use cases.<sup>140</sup>

State APCD agencies may be required to—or choose to—limit the data they collect or modify how they collect it to minimize their exposure to protected information.<sup>141</sup> While such methods can be effective in preserving data privacy, they have the potential to also limit states from pursuing important analytic use cases that require such information (e.g., identifiers to support record linking). States should carefully consider the analytic implications of limiting data intake, as decisions will likely be difficult to reverse; should states decide to restrict data intake, they should consider the latest de-identification practices and technologies that may allow states to achieve their data privacy goals while maximizing data utility.

## Protecting Data Privacy: Data Management, Access, and Use

State APCD agencies can set rigorous standards for how the data they steward is secured against external attack or unintended breaches, and institute data management practices that limit how many staff might ever have access or be exposed to PHI.

The CedarBridge Group’s environmental scan found that half of APCD states were silent or nearly silent on their data security measures, reflecting industry trends of not releasing public information on their practices (in part, to protect data security).<sup>142</sup> Of the APCD states that disclosed their data security practices, about 38% cited compliance with HIPAA and/or Health Information Technology for Economic and Clinical Health (HITECH) security provisions, and 62% described practices that may extend beyond HIPAA/HITECH.

Broadly, HIPAA’s Security Rule requires covered entities to maintain administrative, technical, and physical safeguard for protecting electronic PHI (e-PHI), including:

- “Ensuring the confidentiality, integrity, and availability of e-PHI they create, receive, maintain or transmit;
- “Identifying and protecting against reasonably anticipated threats to the security or integrity of the information;
- “Protecting against reasonably anticipated, impermissible uses or disclosures; and
- “Ensuring compliance by their workforce.”<sup>143</sup>

States may adopt HIPAA as their security standards to avoid market confusion and the need to create and manage new requirements. HIPAA comprises “well known and understood privacy and security requirements ... [and] provides assurances to patients that their data will be protected by measures they are accustomed to.”<sup>144</sup> Colorado’s APCD, stewarded by CIVHC, for example, is legislatively required to comply with HIPAA’s privacy, security, and breach requirements; following these protocols has not prevented Colorado’s APCD data from being among the most widely released and used APCDs nationally.

The MHDO, Maine’s APCD data agency, has its APCD data security, storage, and transmission policies set by the state’s Office of Information Technology (OIT). OIT established HIPAA as the baseline data security requirement while also requiring compliance with other federal data security standards and industry best practices.<sup>145</sup> MHDO maintains a data warehouse that resides within a protected SOC II HIPAA-compliant environment established in accordance with NIST 800-53 (“Security and Privacy Controls for Information Systems and Organizations”), among other federal guidelines.<sup>146</sup> OIT requires MHDO to conduct an annual assessment of its security policies and procedures, provide workforce training, and appoint security and privacy officer to identify and analyze risks in its systems and processes.

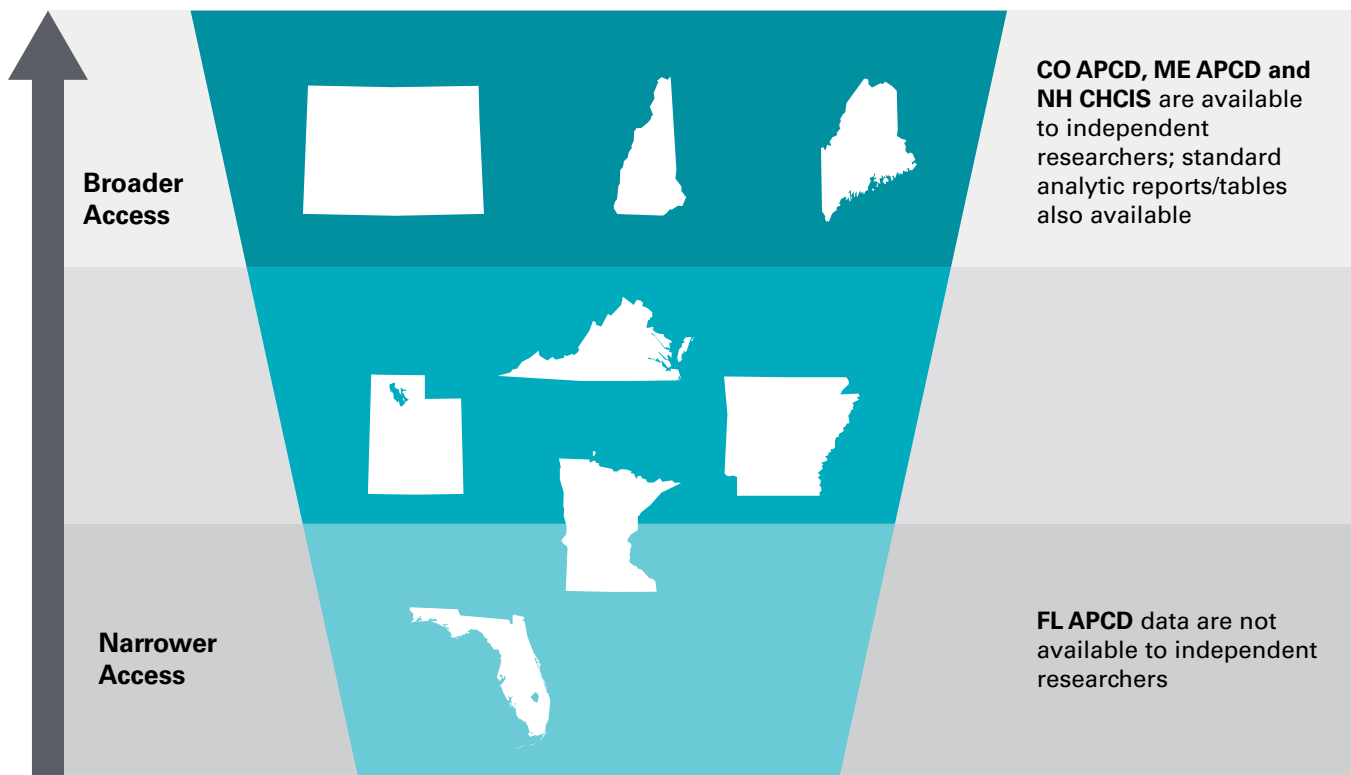
Beyond protecting APCD data—whether in motion or at rest—state APCD agencies frequently institute practices to minimize how many staff can be exposed to sensitive health information. For example, most state APCD agencies require that payers encrypt inbound data transmissions and, upon arrival, “hash” patient identifiers to minimize the risk of patient re-identification, even in an APCD’s production (i.e., working) environment. State APCD agencies may then choose to remove even hashed patient-identifiable data before migrating files into their more broadly accessible internal “analytic” environments. MHDO, for example, “segregates [PHI] from the rest of the data in its own access-controlled scheme by an automated process ... and performs ‘integer substitution’ on certain fields” to protect data privacy even within the organization.<sup>147</sup>

To the extent states set data security practices that differ from HIPAA, they should carefully consider the ongoing governance needed to ensure practices remain current with modern data privacy and technology standards. State APCD agencies benefit from regular data risk assessments that assess how PHI exposure can be minimized from data intake through analytics, including how early in the data intake and data file production process de-identification can occur without jeopardizing data utility.<sup>148</sup>

### Protecting Data Privacy: Data Release

State APCD agencies further protect data privacy through the establishment of defined data use and release regulations, policies, and practices, determining which entities are allowed to get access to what data for what purpose and through what governing process such determinations are made. State regulations, policies, and practices for APCD data release can vary considerably.<sup>149</sup> Some states limit external data access entirely, while others limit access to specific organizations and purposes.<sup>150</sup>

**Exhibit 10: State APCD Data Access for Public Use (For Illustrative Purposes)<sup>151</sup>**



For example, Florida’s APCD data is only available to the state’s Center for Health Information and Transparency staff, with use focused on meeting legislatively required price transparency objectives, such as supporting the public price comparison website, Florida Health Price Finder.<sup>152,153</sup> Since its founding in 2008, Minnesota’s APCD has similarly limited data access to “staff at the [MDH] or organizations working under

contract with MDH to conduct research on its behalf” due to privacy concerns, though it has made recent advancements to liberate its data for broader use, including making several large, summary-level public use files available and releasing a series of [Public Use File Dashboards](#), complementing its novel reporting.<sup>154,155</sup>

Conversely, Colorado’s [CIVHC](#), steward of the [Colorado APCD](#) since 2012,<sup>156</sup> is empowered by legislation to—in accordance with federal and state consumer privacy rules and regulations—“release data to any entity looking for information to support improving health, improving care, and lowering costs for Coloradans.”<sup>157</sup> CIVHC supports over 100 nonpublic data releases and reports annually to “state agencies, employer purchasers, providers, hospitals, and payers,” with data sets often customized to meet stakeholder needs.<sup>158</sup> CIVHC complements data releases with a [variety of public data sets and reports](#).

Massachusetts’ CHIA is similarly statutorily empowered to release—in accordance with federal and state consumer privacy rules and regulations— data to government entities as well as “providers, payers, [and] researchers” for use in advancing “public policy research.”<sup>159,160</sup> In 2021, the MA APCD supported over 15 external research publications, many from institutions based in the Commonwealth, as well as several of its own publications.<sup>161</sup>

Among state APCD agencies where data release is allowed, data release governance practices differ. The CedarBridge Group’s environmental scan found that among APCD states that allowed for data release:

- A quarter maintained a data release committee to review and/or approve data requests;
- 44% maintained multiple committees to review and/or approve data requests (e.g., data privacy committee, data release committee); and
- 12% explicitly required Institutional Review Board (IRB) approval for the release of PHI.<sup>162</sup>

Maintaining rigorous data release governance processes ensures that APCD data leaves state APCD agencies only for the purposes and to the entities the state has determined appropriate.

For example, Massachusetts’ CHIA requires nongovernmental entities seeking MA APCD data to complete a detailed data request application, including a data management plan, and undergo reviews by an internal data privacy committee (minimum data and regulatory compliance reviews) and an external data release committee (public interest and regulatory compliance reviews), and receive executive director approval before data release.<sup>163,164</sup> Approved applicants must then execute CHIA’s data use agreement (DUA) to receive the data.<sup>165</sup> This process can take several months to complete, from initial application to reviews to data receipt. Nongovernmental entities are typically only allowed to access MA APCD files in a CHIA-defined limited data set format, with limited optional enhancements.<sup>166</sup>

Colorado’s CIVHC requires state agencies or private entities seeking CO APCD data to similarly complete a data request application, including data management questions, though it offers a more streamlined review process for many applications.<sup>167</sup> Applicants may request one of four de-identified “standard data sets” or “custom data sets,” which, if also de-identified and assessed to be “consistent with the statutory purpose of the APCD, will contribute to efforts to improve health care for Colorado residents and complies with the requirements of HIPAA,” does not need to be reviewed by CIVHC’s Data Release Review Committee

(DRRC).<sup>168,169</sup> Approved applicants must execute CIVHC's DUA to receive data.<sup>170</sup> CIVHC advises that standard data sets are typically delivered within "two to three weeks after data licensing documents are signed," while custom data sets may take "45 to 60 days."<sup>171</sup>

California's APCD agency, the Department of Health Care Access and Information (HCAI), plans to convene a data release committee in December 2022 to set release guidelines for its in-development APCD, the HPD.<sup>172</sup> However, per the HPD's founding statute, external access to personal identifiers will require the approval of the agency's IRB, the Committee for the Protection of Human Subjects.<sup>173</sup> Incorporating IRB approval into APCD release protocols, particularly for PHI or other sensitive data, is an increasing trend among APCD states.<sup>174</sup>

Where APCD data release is granted, some states may further limit what data is allowed to exit the state environment. For example, the MHDO removes all medical claim lines containing SUD-related codes to maintain compliance—as it interprets it—with federal regulations (i.e., 42 CFR Part 2).<sup>175</sup>

States set a balance between protecting data privacy and supporting data utility through their decisions around data collection, data management, access and use, and data release.

### C. The Role of Vendors in Supporting State APCD Operations

State APCD agencies contract with vendors to support a wide range of technical, technological, and analytic needs. Vendors can support state APCD agencies by:

- Leading payer data collection and curation, including quality assurance, data normalization, and change management processes;
- Managing the data and analytic environment, ensuring compliance with the latest state and federal security requirements;
- Managing data de-identification to maintain patient privacy compliance with federal and state data privacy regulations (e.g., 45 CFR 164.514);
- Developing "value added" fields and functions required to support analytic use cases, including clinical/diagnosis code groupers, master member indexing,<sup>176</sup> and master provider indexing;<sup>177</sup>
- Providing analytic support for the development of products ranging from data dashboards to recurring reports;
- Licensing core data management and analytic technologies; and
- Serving as "staff extenders" if the state is unable to hire due to market conditions or program financial uncertainty, or needs to hire faster than state practices allow.<sup>178</sup>

Every state APCD agency contracts with vendors for some level of support or some type of technology/software. Contracting can allow states to establish APCDs and key functionalities faster, and often less expensively, than developing such capacity internally. It can also allow agencies to better compete with the private market for professional staff, without making long-term employment commitments or investing in extended recruitment and hiring periods.



Major state APCD data management, analytic, and technical assistance vendors include those listed in [Exhibit 11](#), though the field continues to grow. State APCD agencies may also find support from local HIEs, as many seek to serve as regional health data utilities,<sup>179</sup> and even peer APCD agencies, as several seek to share their operational expertise and lease excess data capacity.<sup>180</sup>

**Exhibit 11: Major State APCD Vendors<sup>181</sup>**

Vendor	Types of Services Offered <sup>182</sup>		
	Data Management	Analytics	Technical Assistance and Other Services <sup>183</sup>
BerryDunn		X	X
CedarBridge Group			X
Comagine Health		X	
Freedman HealthCare		X	X
Health Care Cost Institute (HCCI)	X	X	
Human Services Research Institute (HSRI)	X	X	X
MedicaSoft	X		X
Merative (formerly IBM Watson Health)	X	X	
Milliman MedInsight	X	X	X
Onpoint Health Data	X	X	X
Optum	X	X	
NORC at the University of Chicago	X	X	X
SymphonyCare	X	X	

Note: Manatt does not typically contract with state APCD agencies to provide support in these areas. Manatt supports states in understanding how they may leverage existing data resources, including APCDs, to strategically advance program and policy goals and, where necessary, advise on the development of new data assets.

Most state APCD agencies procure vendors to support data collection and curation, with ACHI, steward of the AR APCD, and Massachusetts' CHIA, among the notable exceptions.<sup>184</sup> Vendors offer states an efficient way to establish data collection capacity, immediately bringing lessons learned from other state APCDs—and often similar sets of payers—to bear in operational design. Vendors like Onpoint Health Data, HSRI, Milliman MedInsight, and NORC are also increasingly offering contracted states the ability to compare their data and analytic findings.

Vendor contracting also has drawbacks. Operationally, having a data collection intermediary can distance state APCD agency staff from payers, limiting opportunities to build direct payer relationships as well as institutional knowledge of payer data and data practices, a critical asset for the development of accurate, contextualized reporting. Outsourcing core data functions can also structurally change a state APCD agency's future operational and budgetary needs and introduce new periods of significant operational uncertainty. Vendor contracts for data collection and curation can range from \$750,000 to \$1.4 million for a midsize state, depending on contract scope.<sup>185,186</sup> Vendor scopes offer operational certainties but also rigidities; if state APCD data collection processes need to change or expand, for example, and scope amendments are required, changes can take time to negotiate, and costs can quickly escalate without many agency alternatives. Vendor re-procurements and transitions also have the potential to be disruptive to state APCD agency operations as agencies strive to maintain contractual, program, and other stakeholder reporting deadlines.<sup>187</sup> Contracting with vendors for capacity is akin to leasing capacity and results in less institutional infrastructure that may be built upon should the vendor depart or vendor contracting become prohibited or prohibitive.

State APCD agencies should carefully consider which services and functions they may wish to contract for, along with the benefits and risks of doing so. Having effective strategies to manage and coordinate vendor efforts is a key strategic issue for every state APCD agency.

## D. State APCD Financing

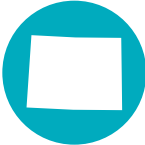

The costs of state APCD operations can annually range from approximately \$800,000 to in excess of \$8 million depending on the scale of the state's analytic program, averaging approximately \$3.5 million for a midsize state with modest analytic capacity.<sup>188,189</sup> State APCDs may require higher up-front costs as data collection and analytic capacity is established. Florida, for example, estimated its APCD information technology-related startup costs at approximately \$3.7 million with subsequent recurring costs of approximately \$600,000 annually.<sup>190,191</sup>

Most state APCD agencies receive at least 75% of their revenue from General Fund dollars, which can create annual financial uncertainty, particularly during changes in Administration (see Section IV.4).<sup>192</sup> However, some states have institutionalized industry assessments to cover what would otherwise be General Fund appropriations, making the cost of running their APCD—and more broadly their state HDO—net zero in the state's budget. For example:

- Massachusetts' CHIA's operating budget is defined by the Legislature, with its revenue is funded by an assessment on local acute hospitals and ambulatory surgical centers and payers.<sup>193</sup>
- MHDO's operating budget is similarly authorized by the Maine State Legislature in its biennial budget, then assessed—by varying proportions—on hospitals, payers, non-hospital health care facilities, and TPAs.<sup>194</sup>

## Medicaid Matching Funds

State APCD agencies are increasingly accessing Medicaid matching funds to support a portion of their APCD expenditures. According to a 2018 analysis by Freedman HealthCare, at least seven states are receiving federal Medicaid matching funds: Colorado, Florida, New Hampshire, New York, Oregon, Rhode Island, and Utah.<sup>195</sup> Federal financial participation (FFP) rates vary depending on the type of funding authority pursued (e.g., Medicaid administrative activities typically at 50% match, Medicaid systems activities typically at an enhanced 75% or 90% match) and cost allocation and use cases approved (see callout).<sup>196</sup> State APCD agencies may be eligible to receive federal matching funds for APCD operational expenditures of up to—or in some cases exceeding—the proportion of their APCD’s population that are Medicaid enrolled, depending on how APCD data is expected to be used.

State APCD Funding: FFP in Practice	
	<p><b>Colorado</b></p> <p>In 2018, Colorado’s APCD agency, CIVHC, worked in partnership with the Colorado Department of Health Care Policy &amp; Financing (HCPF) to petition CMS for 50-50 matching funds to offset the proportion of APCD operations related to Medicaid (estimated at 31% of operating costs).<sup>197</sup> CIVHC and HCPF’s proposal was approved and, in late 2020, further expanded to include a 90-10 Medicaid match for the development of “Medicaid deliverables and tools.”</p>
	<p><b>Washington</b></p> <p>Washington State’s APCD (WA-APCD) was also recently approved for a 50% FFP for up to 35% of expenditures (i.e., 17.5% of total costs).<sup>198</sup> Not all APCD states presently leverage federal Medicaid matching funds to support their APCDs, partially due to the complexity of negotiating arrangements across state departments and with CMS.</p>

## Federal Grant Support (Historical)

The federal government has played a significant, though historically indirect, role in supporting state APCDs, offering states flexible funding opportunities, which many have used to design, implement, and sustain local health data capacity. Many current APCD states were prior recipients of CMS Center for Medicare & Medicaid Innovation (CMMI) ACA State Innovation Model (SIM) and Center for Consumer Information and Insurance Oversight (CCIIO) State Flexibility grants from 2013 to 2016.<sup>199</sup>

In April 2013 and again in February 2015, CMS’ CMMI released grants through its SIM initiative to accelerate state health system transformations that would improve care quality, lower costs, and improve health.<sup>200</sup> These grants, totaling \$960 million, were used by many states to plan for, design, and/or implement APCDs, including:

- Delaware, New York, and Rhode Island, which used their SIM Test Grants to implement their APCDs, the Health Care Claims Database (HCCD), All Payer Database (APD), and HealthFacts RI, respectively;<sup>201</sup>
- Washington State, which used SIM Test Grant funds to expand its APCD reporting and activities;<sup>202</sup> and
- New Mexico, which used its SIM Planning Grant funds to develop its initial APCD design, which it is now working to implement.<sup>203</sup>

CCIO's Cycle III Rate Review Grants played a similar, concurrent role in supporting state APCD development. In September 2013, CCIO made \$67 million in grant funding available to states, with 11 states using funds to support APCD development and maturation.<sup>204</sup> Arkansas and Hawaii used Rate Review funding to establish their APCDs.<sup>205</sup>

AHRQ has also demonstrated a persistent interest in state APCDs and how they may be used to "advance the goal of improving health care affordability, efficiency, and cost transparency."<sup>206</sup> In 2017, AHRQ sponsored a series of reports that discussed the state APCD environment, common use cases, barriers to success, and opportunities for developing cross-APCD-based measures. It convened a technical expert panel (TEP) to guide it through these investigations. AHRQ has also provided regular grant funding to NAHDO, the national APCD convening organization, to support state conferences, convenings, and other cross-state knowledge-sharing activities.<sup>207</sup>

As previously discussed in this paper, federal interest in state APCDs continues to grow. The state APCD capacity building grants authorized by the CAA of 2021 have recently been resurrected by the U.S. House Appropriations Committee, and in August 2022, ASPE and AHRQ convened a new TEP to guide the development of a "national APCD," for which AHRQ has requested funding to support, starting with a multi-state APCD pilot project.

Federal interest in supporting state APCDs is currently high in both the executive and legislative branches, and across parties, with bipartisan support for the type of market transparency that APCDs can provide.

### **Other Revenue Sources**

State APCD agencies may also receive funding support from APCD data licensing and use fees (see Section III.A), philanthropic grant funding,<sup>208</sup> and fees generated from inter-agency data-sharing agreements to support targeted analytics.

## **E. Federal Interest in Establishing a National APCD**

The value of state APCDs, the need for greater cross-state APCD systemization, and the potential for greater data centralization have not gone unnoticed by the federal government.

### **2010: HHS Multi-Payer Claims Database**

Between 2010 and 2013, the HHS ASPE, in partnership with CMS, supported early-stage planning for a national MPCD that would combine public and private payer claims data to support comparative effectiveness research (CER).<sup>209</sup> Funded by the American Recovery and Reinvestment Act of 2009 (ARRA), the pilot project comprised four phases:

- Developing a basic framework for MPCD operations;
- Piloting data integration;
- Developing a user-interface prototype; and
- Implementing the MPCD.<sup>210</sup>

The first phase of the project was completed in 2010, recommending a “hybrid approach with state-based component” that would allow for centralized data requests and aggregation for state and national data. A governance board was established to guide implementation in 2011, and in September 2012, ASPE launched “beta testing” of the MPCD, wherein its contractor supported three CER analyses.<sup>211</sup> MPCD pursuit after beta testing appears to have been limited before the effort was ultimately shuttered due to changing political priorities and operationalization concerns. Any new national APCD pursuit should explore the lessons learned from the MPCD effort to avoid similar pitfalls.

### **2019: Lower Health Care Costs Act (LHCC)**

In June 2019, the U.S. Senate Committee on Health Education Labor and Pensions (HELP) approved the LHCC Act by a vote of 20 to 3, enjoying broad bipartisan support as it consolidated 54 proposals from 65 senators, including the establishment of a federal APCD that would address national APCD data completeness resulting from Gobeille.<sup>212</sup>

#### **LHCC Act Provisions**

The LHCC Act would have required DOL to “enter into a contract with a nonprofit entity to support the establishment and maintenance of a database that receives and utilizes health care claims information and related information and issues reports that are available to the public and authorized users” and submit such reports to HHS, among other federal agencies and advisory bodies. It sought to establish the database to “improve transparency by using de-identified health care data” to:

- “Inform patients about the cost, quality, and value of their care;
- “Assist providers and hospitals, as they work with patients, to make informed choices about care;
- “Enable providers, hospitals, and communities to improve services and outcomes for patients by benchmarking their performance against that of other providers, hospitals, and communities;
- “Enable purchasers, including employers, employee organizations, and health plans, to develop value-based purchasing models, improve quality, and reduce the cost of health care and insurance coverage for enrollees;
- “Enable employers and employee organizations to evaluate network design and construction, and the cost of care for enrollees;
- “Facilitate State-led initiatives to lower health care costs and improve quality; and
- “Promote competition based on quality and cost.”

The database was envisioned as a resource to support health care transparency, research, quality improvement, and cost containment.

The LHCC Act’s national APCD would have been responsible for collecting data from self-insured group health plans and TPAs<sup>213</sup>—as well as all data that would be available to a QE, such as Medicare data—and distributing it back to states in exchange for states’ non-self-insured data, a model similar to that proposed in

this paper (see Section V).<sup>214</sup> The LHCC Act would have further directed DOL to “issue regulations prescribing the extent to which, and the manner in which” the HIPAA Privacy, Security, and Breach Notifications would apply to the database, and “in order to ensure data privacy and security... issue supplemental regulations.”

### LHCC State Grant Provisions

The LHCC Act would have also granted the HHS Secretary, in consultation with the Secretary of Labor, the authority to award up to \$100 million in grants over ten years to states “for the purposes of establishing and maintaining State [APCDs] that improve transparency of data,” which would have been among the largest federal investments in building state health data and analytic capacity since HITECH. Further, with funding tied to state APCD alignment with a common data collection format, the bill’s provisions would have likely resulted in rapid harmonization of state APCD data collection specifications nationally, addressing a major current state APCD limitation discussed in this paper.

### Stakeholder Input and Reactions

The bipartisan LHCC Act was informed by broad, bipartisan input in its preceding years, and received broad bipartisan support upon its release, though it ultimately failed to pass deliberations in the broader Senate chamber.

As early as 2017, the **State of New Hampshire’s Insurance Department** sought congressional action in response to the Supreme Court’s *Gobeille* decision (see Section IV.2.1), sending the following note to the Senate HELP Committee and Senator Lamar Alexander, its ranking member, which followed up on similar correspondence with House Majority Leader Kevin McCarthy:

The cost transparency focus in New Hampshire predates the ACA, and enjoys strong bipartisan support as a free-market initiative focused on the cost of health care. Fostering data transparency has encouraged competition at the health care provider level and led carriers to develop plan designs that encourage the use of low-cost, high-quality care providers. [New Hampshire uses its APCD] claims data to better understand the most pressing health issues in the state, including, as we face an opiate addiction crisis, analyzing claims cost data to establish prevalence levels in the commercially insured population and identify[ing] treatment patterns... New Hampshire’s market analysis of [APCD] claims data support[s] a finding that transparency enhanced competition by helping both insurance carriers and providers better understand the market in which they are operating and thereby creating increased price sensitivity.

In the wake of *Gobeille*, which “hampered states’ authority to collect claims data with respect to self-funded employer coverage,” and whereas “fully capturing the data from all covered persons is important to maintaining an accurate understanding of health care costs,” New

Hampshire sought a [c]ongressional solution to “amend ERISA to expressly authorize state insurance regulators to collect health care claims data on an anonymous basis with respect to both fully insured and self-funded coverage.”<sup>215</sup>

In advance of the LHCC Act formally being introduced, in March 2019, representatives from the **American Enterprise Institute** and the **Brookings Institution** shared a letter with HELP Committee Chairman Lamar Alexander, that advocated for creating a “pathway to encourage the development of APCDs.” The letter shared:

“One significant barrier to both public and private sector efforts to reduce health care spending is a lack of detailed and comprehensive data on provision and consumption of health care services, particularly among people enrolled in private insurance. Without high-quality, comprehensive data, it is difficult to obtain an accurate picture of how the health care system is operating today, which in turn makes it challenging to devise strategies to make it work better. In recent years, many states have aimed to address this problem by establishing [APCDs],” but were “dealt a significant blow” by the Supreme Court’s *Gobeille* decision, which left “large gap[s] in states’ APCD as self-insured plans account for around half of all enrollment in private health insurance nationwide.

“The federal government should take action to enable state APCDs to collect data for self-insured plans. It has at least two options for doing so. First, the Department of Labor likely has the authority to create a standardized national process that state APCDs could use to collect data from self-insured plans without running afoul of ERISA. Congress could direct the Department to use that authority. Second, Congress could clarify that ERISA was not intended to bar state APCDs from collecting data from self-insured plans and thereby permit states to move ahead without additional federal action.”<sup>216</sup>

Stakeholder responses to the LHCC Act’s APCD provisions, were similarly positive but not uniform, along traditional lines, nor absolute. Health care employer groups, purchasers, and industry associations, generally, came out as supporters of the federal APCD.

The **ERISA Industry Committee (ERIC)**, a strong protector of ERISA and a regular and vocal protestor of state APCD overreach on ERISA data collection since *Gobeille* (as previously discussed), notably supported the proposal:

ERIC supports the creation of a national APCD to fill data gaps for states, empower plan sponsors with data, and ensure that ERISA plans are not subject to state efforts to implement claims data reporting regimes.

ERIC has endorsed the creation of a national APCD that aggregates large employer claims data, as well as state-level and fully-insured data, and Medicare data, giving employers and researchers the opportunity to get a comprehensive view of health care markets and trends. We believe this section of the legislation strikes the right balance in respecting states’ rights to create their own databases, ensuring states get access to the multitude of data they currently do not have access to, and protecting the ability of ERISA plans to operate on a national, uniform level. Critically, this section should put to rest any continuing attempts by states to impose reporting requirements on ERISA plans. While we believe the U.S. Supreme Court’s *Gobeille* decision makes clear that ERISA plans are not subject to these state efforts,

we acknowledge that states can make use of self-insured claims data—just as self-insured plans can make use of a comprehensive database that includes fully-insured data and public employee/public plan data. As such, ERIC supports this federal solution.

ERIC encouraged the committee to expand the eligibility criteria for potential federal APCD vendors, and suggested expanding the scope of authorized users to include HIT companies and “academic and private sector researchers and innovators.”<sup>217</sup>

The **American Benefit Council** was also “generally supportive of the establishment of an all-payer claims database at the federal level,” though expressed concerns that the proposal was too limited and would “create a self-funded group health plan-only payer claims database, since it would not impose like reporting requirements on the other significant payers in our health care delivery system,” and encouraged the committee to ensure the “reporting obligations be applied more broadly to all relevant payers in the system.” The Council further noted that the “provision appears largely redundant to the current requirements imposed on group health plans and health insurance issuers through Section 2715A of the [Public Health Services Act (PHSA)] and, by incorporation, Section 715 of ERISA,” suggesting that new authority was not necessarily needed, but if pursued, should replace the current requirements, which would “ensure the most comprehensive set of reporting data and eliminate the potential that group health plans and health insurance issuers are subject to duplicative and administratively burdensome reporting requirements.”<sup>218</sup>

The **Purchaser Business Group on Health (PBGH)** “strongly support[ed] the key elements of Section 303, which would establish a non-governmental not-for-profit organization to create an [APCD].” PBGH noted its belief that the federal-APCD “can be designed in a way that protects patient privacy and allows state-level APCDs to exist within a federal structure.”<sup>219</sup>

The **American Hospital Association (AHA)** responded positively, “recogniz[ing] the potential of APCDs to drive quality improvements and cost-containment, as well as helping to identify and track issues within the healthcare system.” AHA offered recommendations to strengthen the bill, including increasing its patient privacy and security provisions, requesting that data released in the federal APCD’s annual report be “presented in full context,” and that “stakeholders be involved in the governance process.”<sup>220</sup>

**America’s Physician Groups (APG)** also “supported” the creation of a “federal [APCD], excluding capitated and risk-based arrangements, for self-funded plans... in order for benchmarks and ultimately best practices to be identified.” APG cited the “recent addition of Medicare Advantage claims data to the Medicare database” as an example of how expanded claims data access “has assisted [its] members in identifying benchmarks and best practices.”<sup>221</sup>

However, the APCD provisions did have several public opponents.

The **U.S. Chamber of Commerce** expressed reservations, concerned about disclosure of payer-provider “contract terms and negotiated reimbursement rates,” patient privacy protections, and an operationally “unrealistic timeframe.” The Chamber proposed an alternative model that would “require that all issuers and [TPAs] serving self-funded employers make data available to ... employers directly, using a distributed data approach to collect data for defined research purposes, and investing in state APCDs.”<sup>222</sup>



**AHIP**, a national health plan association, also came out in strong opposition to the bill: “[W]e are concerned about provisions that would represent a major government overreach into the private market,” including its requirements to “disclose competitively negotiated, proprietary rates.” AHIP noted that it “fully support[s] transparency that help[s] consumers make informed decisions about their care and costs. And we are committed to collaborating on solutions that bring down costs. We will continue to work with Congress and the Administration to improve health care affordability and access for every American.”<sup>223</sup>

The APCD provisions were among many in the expansive LHCC Act health care reform bill, and ultimately died with the rest of the bill out of committee. Stakeholders had substantial concerns about the bill’s surprise billing provisions and about federal government encroachment into private markets.<sup>224</sup> While the LHCC Act failed to gain momentum in the full Senate, its APCD provisions were a milestone, highlighting renewed federal interest in creating a national claims and encounter data repository and acknowledging the role the federal government could play in resolving state APCD challenges.<sup>225</sup> Its echoes would be heard in the No Surprises Act and other congressional proposals in 2020.

### **2020: Congressional “Federal APCD” Proposals**

After the LHCC Act failed to advance, several bills were introduced in Congress in 2020 explicitly calling for a “Federal APCD,” though none made it far in the legislative process.

On February 27, 2020, Congressman Lipinski (IL) introduced H.R. 6004, the “Transparency and Accountability in Health Care Costs and Prices Act of 2020,” which would have:

- Established a federal grant program to support states in establishing or maintaining an APCD;
- Required state APCDs receiving grants to make information from those databases available to the Congressional Budget Office, Comptroller General of the United States, and the Medicare Payment Advisory Committee (MACPAC) and Medicaid and CHIP Advisory Committee (MedPAC), upon request; and
- Included a provision that would have amended ERISA to require “group health plan[s] (including a self-insured group health plan) to provide claims data” to an APCD.<sup>226</sup>

The bill was referred to the Committee on Energy and Commerce and the Committee on Education and Labor and was not brought up for a vote.

Later that year, on December 15, 2020, Congressman Beyer (VA) introduced H.R. 8967, which would have directed the HHS Secretary “to award a contract to an eligible nonprofit entity to establish and maintain a health care claims database for the purposes of lowering Americans’ health care costs, and for other purposes.”<sup>227</sup> The bill would have established a federal APCD that would collect data from:

- Group health plans through “its sponsor, TPA, pharmacy benefit manager, or other entity designated by the group health plan”;
- Medicaid data from CMS;
- TRICARE data from the Department of Defense; and the
- FEHB Program data from the Office of Personnel Management (OPM).

State APCDs could get access to federal APCD data in exchange for the data they collected. It also proposed a clerical amendment to ERISA to stipulate group health plan and issuer compliance with its provisions. The bill was similarly referred to committee and never reached a broader vote.

### **2020: No Surprises Act's APCD Surprise**

Congress reapproached state APCD policymaking with more incremental proposals in late 2020. In the No Surprises Act and the CAA of 2021, the federal government:

- Authorized state grants of up to \$2.5 million over three years for each state to establish or enhance an APCD in exchange for fulfilling various reporting and data access requirements;<sup>228</sup> and
- Established an SAPCDAC to provide recommendations to DOL on data standards that could be promulgated to allow for the consistent and voluntary state collection of self-insured data.<sup>229</sup>

While the CAA again demonstrated the federal government's interest in resolving some of state APCD agencies' greatest challenges—limited funding and missing self-insured data—its impact was minimal. State APCD grants have not yet been appropriated (see call-out), and after receiving the SAPCDAC's recommendations, the DOL has not yet advanced policies that would meaningfully change the current state of APCD self-insured data collection.<sup>230</sup>

#### **APCD Grant Updates**

In June 2022, the U.S. House Committee on Appropriations included funding in its appropriations bill to support up to \$1 million of APCD capacity-building funding for up to 25 states and to further the work being undertaken by AHRQ and ASPE to assess and build national "APCD infrastructure."<sup>231</sup> At the time of this paper's publication in November 2022, it is unclear whether funds will be ultimately appropriated by the Senate.<sup>232</sup>

## 2022: Executive Agency APCD Interest and Action

Federal agency interest in state APCDs and how their data can be used to support cross-state use cases has been renewed in the wake of the COVID-19 pandemic, where federal leaders lacked access to broad and responsive health system data. In its Federal Fiscal Year (FFY) 2023 budget, AHRQ requested \$5 million to “advance HHS efforts to coordinate and align on-going state-level efforts to develop [a] national-level” APCD. The envisioned national APCD would have:

Data linkage capacities to join claims and administrative data with other data resources to facilitate research. AHRQ will partner with states and other data holders to create a framework for a secure national-level APCD that will enhance value to individual participating states and provide analytics to federal policy makers to inform decision making. The database will have the capacity to track patients across care settings, over time, and to the extent possible, across geographic locations. These features will enable research on national health priorities including COVID, the opioid epidemic, maternal mortality, cancer, and many more ...<sup>233</sup>

As proposed, AHRQ’s national APCD would collect “population-based sample[s] of insurance claims that [would] be used to inform public and private policy, address equity issues, and to improve healthcare quality.” If approved, AHRQ would conduct an environmental assessment to confirm its approach and likely pilot a multi-state APCD data collaboration effort to test its proof of concept. This paper was designed to inform federal considerations on the efficacy of a national APCD and more broadly support federal and state collaboration to enhance the state APCD operating model.

As federal and state policymakers and regulators, researchers, purchasers, and consumer advocates seek more information about our health care system (see callout for other recent federal data actions), and as major states establish their own APCDs, a coordinated national model for APCD data collection and use has never been more important. The coming year presents federal, state, and industry stakeholders an opportunity to recast our nation’s APCD model and establish the data resources needed to better monitor America’s largest industry—our system of health—and how it is serving Americans.

## Other Recent Federal Actions to Liberate Health Care Market Data

In recent years, the federal government has taken steps to ensure consumers have greater access to their health information and payer and provider pricing information to support their decision-making (and encourage market competition). While these actions have resulted in more health information reaching the public, they have not produced the type of comprehensive and versatile data resources state policymakers, regulators, purchasers, and other stakeholders often seek to support market oversight, policymaking, and purchasing.

**Consumer Data Access:** The 21<sup>st</sup> Century Cures Act, signed in December 2016, set a vision for an interoperable health care ecosystem, where information that Americans needed to make informed health care decisions would be available to them.<sup>234</sup> The act was operationalized by a pair of interoperability rules, released by the Office of the National Coordinator for Health Information Technology (ONC) and CMS in March 2020.<sup>235</sup> These rules established new reporting and technical requirements for payers and providers to ensure Americans could, without special effort, see, obtain, and use their health care data. While these new requirements will allow consumers to have more ready access to their PHI, they did not create data resources that could be easily used to support market oversight.

**Price Transparency:** CMS has advanced new requirements for payers and providers to publicly disclose the prices for health care services to allow consumers to compare prices before receiving care. In 2010, the ACA required that hospitals publicly list their standard charges for items and services.<sup>236</sup> In 2019, CMS' Hospital Price Transparency Final Rule required further disclosure of hospitals' negotiated rates and for information to be shared in shoppable service tools (for consumers) and machine-readable files (for researchers, purchasers, and third-party vendors).<sup>237</sup> In 2020, CMS released its Transparency in Coverage Final Rule, which built on previous actions to require health plans in the individual and group markets to make negotiated rates for health care items and services, including prescription drugs, available to consumers along with out-of-pocket cost information.<sup>238</sup> It also required the release of machine-readable data files. These new requirements will bring new health care service pricing information into the public domain as compliance increases.<sup>239</sup> The new price transparency data will not provide insight into how services are utilized, at what frequency, and by which populations, nor how rates are changing over time and contributing to cost growth. As noted in the Transparency in Coverage Final Rule, "the final rules are only one part of the solution to address issues contributing to the lack of competition in the health care market and resulting increases in health care costs."

The new price transparency data will not provide insight into how services are utilized, at what frequency, and by which populations, nor how rates are changing over time and contributing to cost growth.

## IV. Enhancing State APCD Use and Usefulness: Gaps and Potential Solution Strategies

While state APCDs have demonstrated their capabilities to provide state policymakers and regulators, among other data users, with insight into local markets, the current state operating model has several limitations that can constrain their local and national use and usefulness, including the following:

- **Missing data for key populations and services:** Federal regulations limit the ability of state APCD agencies to collect data from most self-insured plans and federally managed health care programs, creating data gaps for up to a third of state residents.
- **Inconsistent data collection and data access requirements:** Each state APCD agency has its own protocols for how it collects, curates, and releases data, impeding interstate data comparisons and creating reporting burden for data submitters, and data access and analytic burden for prospective multi-state data users.
- **Need for sustainable and adequate funding for state health data capacity:** State APCD agencies—and state HDOs more broadly—typically lack a dedicated funding source, making them dependent upon state General Fund dollars, which leaves them vulnerable to annual state budget cuts, and limits their ability to make long-term infrastructure investments to support pressing use cases and maintain data security standards.

With more than half of states not having an operating APCD, America is also confronting **national data collection gaps**, which limits the potential for national, regional, and cross-state analyses and benchmarking, and which introduces new **state health information inequities** among data “have” and “have not” states.

Understanding these gaps and their root causes—whether legal or regulatory, technical, or operational—is essential for designing an alternative APCD data collection and analytic model that will better serve potential national and local data users and the public good. This section discusses state APCD limitations to supporting local and national use cases and offers potential resolution strategies to address those barriers; neither its listing of challenges nor solutions should be viewed as exhaustive, nor dismissive of the important local investigations that can be supported using state APCDs today.

## Opportunity #1: Support National APCD Data Collection

While 18 states have implemented an APCD as of early 2022, 32 states and the District of Columbia have not, limiting data users’ ability to perform cross-state, regional, and national analyses and creating new health information inequities among states.

### Exhibit 12: Gaps in State APCD Coverage

#### States Covered by APCDs



#### #1.1: Address State APCD Coverage Gaps

State APCDs have been established across the country in states of varying geographies, populations, and political leanings, consistently viewed as an important tool for evidence-based policymaking and market transparency. However, states with APCDs are not evenly distributed across America. Seven APCD states are located in the Northeast (CT, MA, ME, NH, NY, RI, VT), three in the mid-Atlantic (DE, MD, VA), and five—including two in-development (\*)—are on or near the Pacific coast (CA\*, NV\*, OR, UT, WA). This leaves significant swaths of the country without state administrative health data capacity, including many states in the Northern Rockies (ID, MT, WY), Midwest (IA, IL, IN, MO, ND, NE, OH, OK, SD), and South (AL, LA, MS, SC).

While the “clustering” of APCD states has fostered some regional, cross-state analyses (e.g., NESCSO’s cross-state primary care spending analysis), it has also prevented others.<sup>240</sup> For example, regional analyses of health care coverage, access, utilization, and cost trends, including access inequities and outcome disparities, would be limited for:

- The New York Metropolitan Area with state APCD capacity in New York and Connecticut, but not in New Jersey and Pennsylvania;
- The Washington, D.C. Metropolitan Area with state APCD capacity in Delaware, Maryland, and Virginia, but not in Washington, D.C.;
- The Mississippi Delta with state APCD capacity in Arkansas, but not in Louisiana and Mississippi; and
- The Rocky Mountain region with state APCD capacity in Colorado and Utah, but not in Idaho, Montana, and Wyoming.

Supporting the development of new state and/or regional APCD capacity—particularly if paired with a single process for accessing cross-state data—could unlock valuable new use cases for existing APCD states, shine a light on regional issues that require a multi-state view, and engage new data user groups, like multi-state health care purchasers. Stakeholders interviewed for this report identified several “priority” national, cross-state, and regional APCD use cases that are not presently able to be supported due to a lack of regional or national APCD capacity (Exhibit 13).

**Exhibit 13: Examples of High Value Cross-State APCD Use Cases by Purpose**

Purchasing <sup>241</sup>	Public Health	Health System Oversight
<ul style="list-style-type: none"> <li>Identifying cross-state and provider price variation and measures of provider service quality to inform network and benefit design, including assessing the potential establishment of service “centers of excellence”</li> <li>Benchmarking membership service utilization and costs against similar populations</li> <li>Assigning reasonable “proxy prices”<sup>242</sup> for capitated encounters based on similar services provided on a FFS basis</li> </ul>	<ul style="list-style-type: none"> <li>Understanding and addressing cross-state regional health disparities (e.g., Mississippi River Delta),<sup>243</sup> including chronic disease prevalence and prevalence trends</li> <li>Supporting national epidemiological and rare disease studies with data on treatments, hospitalizations, and costs</li> <li>Benchmarking health and service use indicators across states and for specific populations under evaluation</li> </ul>	<ul style="list-style-type: none"> <li>Supporting cross-state market power analyses, including assessing the impact of payer and provider consolidation on local service access and costs</li> <li>Understanding national, cross-state, and regional health care service migration and delivery patterns and pattern changes (e.g., tele-behavioral health)</li> <li>Benchmarking priority service utilization and spending across regions and states (e.g., primary care, behavioral health)</li> </ul>

Data users seeking regional or national claims/encounter data are often forced to acquire data from private health care claims databases, often at steep costs and to mixed effect (see Section II.A). Private health care claims databases frequently lack—or are unable to disclose for analytic purposes—important population characteristics, plan type information, facility-specific information, and data at sub-county geographies.

While policymakers and regulators in states with APCDs may use these resources to understand and test potential policy and program reform proposals (see callout), those stakeholders in states without an APCD remain dependent on narrow federal and state reporting, expensive and limited private claims resources, and ad hoc data requests of payers and providers. Inequities in state health system data access and use may result in institutionalized differences in policy- and program-making responsiveness and effectiveness among states, creating state data “haves” and “have nots” in an environment where states retain paramount responsibility for regulating and overseeing their local markets and supporting the health and well-being of their residents. Having access to comprehensive and cohesive health system data equips states with information to support more responsive, targeted, and effective policymaking.

### State Policymaker Testimony Advocating for the Establishment of an APCD: Nevada

In 2019, Nevada passed Senate Bill 472, which established an APCD in Nevada, pending federal funding, seeking to make “strides toward our goal of healthier, more informed Nevadans.” Per one Senator’s testimony, the bill promised Nevada:

The means for how we can receive better health care with smarter spending. ... Over the past several years, a growing number of states have established a state sponsored APCD system to address the needs of transparency in health care at the state level and support consumers, purchasers and state reform efforts. ... I would like to present examples of ways an APCD system is used to promote transparency and oversight in health care utilization, quality, and cost. Promoting cost and quality transparency and protecting consumers, the APCD cost website in New Hampshire, Maine and Maryland makes available **provider level price and quality information to consumers**, health plan enrollees and employers to **promote health care comparison shopping**.

The Oregon APCD publishes quarterly reports that **compare per member per month cost and utilization services** by category for commercially insured, public employees and public payers. In Colorado, the information has been analyzed to **study price variation for common procedures among health care facilities**. ...The system in Massachusetts has been used to produce an annual report of **trends in health care spending** for commercial payers by category of service, type of episode and geographic area. ... Rhode Island has released a report of the **top 15 clinical complaints and associated costs of potentially avoidable emergency room visits** broken down by payer type. In Minnesota, APCD data has been used to analyze **prescription drug spending by therapeutic category and setting**. They have also released a report estimating the use and **cost of low-value services** in the state. ... Organizations in Virginia and Utah have used APCD data to **track opioid prescription claims** across geographic areas and patient characteristics to understand and address trends. The researchers at Arkansas Center for Health Improvement are using APCD data to understand the impact of Medicaid expansion efforts.

The important point to remember is that **none of these reports would be possible without an APCD system**.<sup>244</sup>

—Senator Spearman, Presentation of SB 472 to the Nevada Senate Committee on Health and Human Services



## Potential Solution Strategies

Common state hesitations in establishing an APCD include ongoing funding availability to sustain operations, a particularly acute concern for states with smaller budgets; data privacy concerns; and proof of utility and value.<sup>245</sup> Stakeholders can pursue several strategies to address these concerns.

### Strategies to Support More Sustainable State APCD Operations

**(1) Provide permanent federal financial support for establishing and sustaining state HDOs that steward APCDs:** While funding the authorized, federal CAA grants for a multi-year period may catalyze several “on the fence” states—including Alaska, Missouri, and Tennessee—to advance APCD development, with minimal APCD operating financial requirements eclipsing \$1 million annually, many states will likely remain hesitant to invest without a permanent and sustained source of funding outside of state General Fund appropriations.<sup>246</sup> CMS, in coordination with the U.S. Office of Management and Budget (OMB), could help address this need by:

- Updating Medicaid cost allocation guidance and Medicaid MES funding guidance via SMD letter regarding state APCD funding to clarify requirements and eligible expenses;<sup>247</sup>
- Expanding federal Medicaid administrative cost allocation guidelines to cover a greater share (match) of APCD operating expenses to the extent the APCD is used for Medicaid-focused market analyses (e.g., benchmarking to identify and advance system change) for the purposes of addressing concerns experienced disproportionately by the Medicaid population (e.g., behavioral health needs/access assessment, dual-eligible analyses);<sup>248,249</sup> and
- Providing new federal-state “health data innovation” funding for state HDOs, which may be used to support APCD development, among other health data capacity investments in support of local oversight and regulatory activities.

**(2) Create options to help states reduce state APCD operating expenses and expand analytic value:**

Identifying and realizing opportunities to scale common state APCD operations could reduce operating costs for individual APCDs, allowing state APCD agencies to reallocate resources to analytic priorities.

(A) Establish federal APCD data collection opportunity: The federal government can establish a national HDO that could provide all states—presently with or without an APCD—payer data collection services. National HDO data collection and redistribution for a state may comprise only ERISA-preempted self-insured data (assuming a common data standard is in place and regulatory authority confirmed) or all state data. The federal government may empower the national HDO to provide data collection and distribution services to state APCDs without charge or at cost, reducing state APCD costs and barriers to entry. The federal model, as discussed later in this paper, may also allow states to access new market (e.g., ERISA-preempted self-insured) and peer state data to support additional use cases and provide greater analytic value to local APCD users, also supporting long-term sustainability.

(B) Promote cross-state, regional APCD data collection services: Mature state APCD agencies, APCD vendors (e.g., Onpoint Health, NORC, HSRI), and HIEs operating as health data utilities, may offer cross-state APCD data collection services—and potentially analytics—to current and prospective APCD agencies, leveraging

scale to reduce individual state costs. The federal government or a philanthropic organization could support the development and implementation of a multi-state data collection pilot and share lessons learned to spur market action.

Redirecting data collection responsibilities to vendors or third parties may require some states to modify local regulations.

#### Strategies to Address Data Privacy and Security Concerns

**(3) Establish uniform minimum data security and privacy standards for state APCDs:** To address one common state hesitation in pursuing an APCD—data security and privacy concerns—a philanthropic organization could fund the convening of federal, state, and industry health data privacy and security leaders and state APCD representatives to collaborate in the development of minimum technical and data privacy standards for state APCDs. Establishing minimum data protections for APCDs and a potential certification process to communicate that such standards have been met could alleviate concerns about individual state APCD practices. Some states may need to modify their guiding regulations to support adoption of common, minimum data security and privacy standards. (See Sections III.B and VI.5 for additional discussion on state APCDs and data privacy.)

#### Strategies to Communicate State APCD Value

**(4) Elevate state APCD best practices to motivate adoption and counter local opposition:** Philanthropic organizations, in coordination with NAHDO and the APCD Council, can develop targeted communications for state policymakers, regulators, and other key stakeholder groups (e.g., National Conference of State Legislatures) that describe how state APCDs may be used to support their policy, program, and regulatory activities and information priorities. Materials may answer common questions and respond to common concerns about APCDs, or speak to program-specific use cases (e.g., how Medicaid programs effectively use APCDs to support mandated benefit-cost analyses, population health monitoring, and program reform planning).

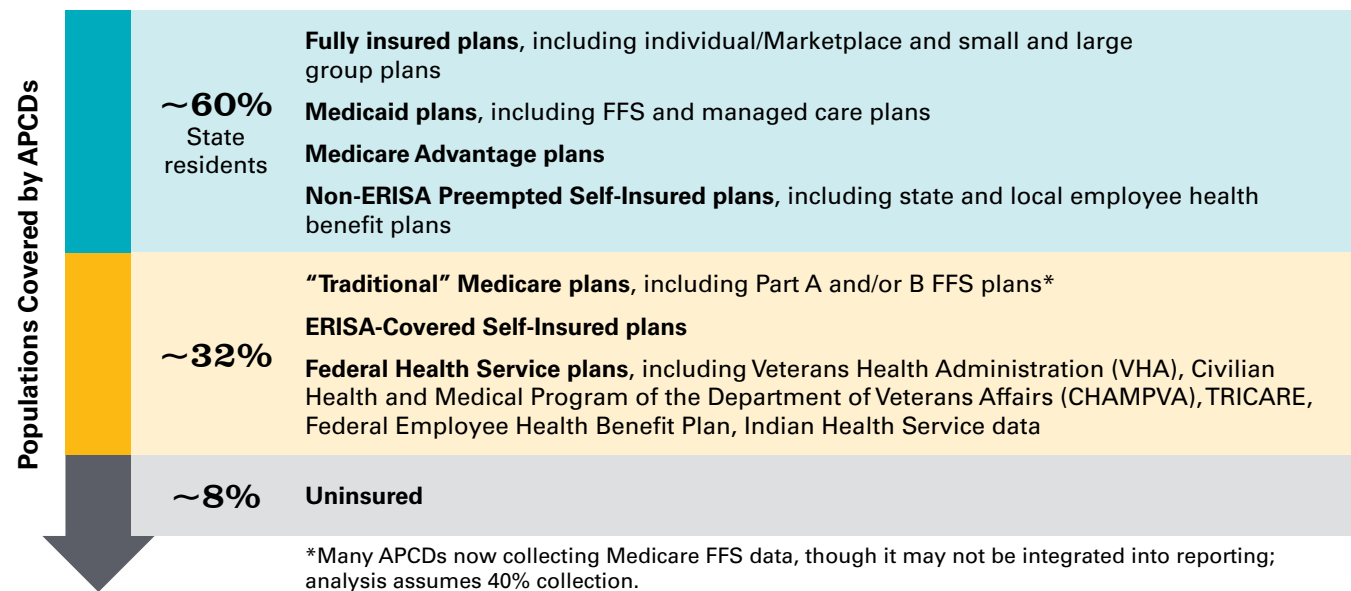
## Opportunity #2: Resolve State APCD Data Gaps

State APCDs must confront challenges in collecting certain federally regulated and administered data, including data for individuals covered by ERISA-preempted, self-insured plans, data for those covered by or receiving health care through federal programs, and data on federally funded SUD treatment services, which is critical for resource use in combatting the opioid epidemic.

### #2.1: Address ERISA-Preempted Self-Insured Data Gap

The biggest data gap for most state APCDs is that of the **ERISA-preempted self-insured**.<sup>250</sup> Approximately one-third of Americans are covered through a self-insured employer plan, and since the Supreme Court’s 2016 *Gobeille v. Liberty Mutual Insurance Co.* ruling, state APCD agencies have been prohibited from requiring payer and TPA data submission for most of those members.<sup>251</sup>

**Exhibit 14: Populations Included in State APCDs**



Missing self-insured data limits the ability of APCDs to support full-market and ESI market analyses. Self-insured employers have different characteristics and their employees and subscribers have health system experiences different from those individuals covered through fully insured plans. Compared with fully-insured employers, self-insured employers are:

- Larger, covering 82% of workers in firms with more than 200 workers, compared to only 21% of workers in smaller firms;<sup>252</sup>
- Located in the Northeast, Midwest, and Southern states, as opposed to Western states, and concentrated in industries like transportation/communications/utilities and retail;<sup>253</sup>
- Enrolled in point-of-service (POS) and preferred provider organization (PPO) plans;<sup>254</sup> and
- May comprise healthier, “lower risk” employees, particularly for smaller self-insured employers.<sup>255</sup>

Missing self-insured data also limits state APCDs' utility to support use cases for multi-state employers and health care purchasers, which are often seeking to benchmark health service costs and quality by state and provider to drive their purchasing and network design decisions. A recent survey from the KFF found that among "large" firms of 500 or more workers:

- Few were aware of what state APCDs were (12%);
- Even fewer contributed to a state APCD (1%);<sup>256</sup> but
- Most saw value in them (51%).<sup>257,258</sup>

Any resolution strategy for resolving ERISA-preempted, self-insured data gaps requires an understanding of the legal issues raised in *Gobeille*, the paths pursued to resolve these issues to-date, and stakeholders' positions in supporting or objecting to pathways forward.

### **State, Federal, and Industry Positions on ERISA-Preempted Self-Insured Data Collection Since *Gobeille***

The reporting of ERISA-preempted, self-insured data to state APCDs largely ceased in 2016 after the Supreme Court's ruling in *Gobeille vs. Liberty Mutual*. State APCD agencies have since explored various pathways for regaining access to this important data to support local use cases. Meanwhile, the federal government, including the executive and congressional branches, has pursued a broad—and broadly bipartisan—health system market transparency agenda that has increased self-insured, group health plan price and spending transparency. The use of existing federal authority to compel self-insured reporting may illustrate a pathway—or present new incentives—for the resumption of ERISA-preempted self-insured data reporting to state APCDs.

#### ***Gobeille vs. Liberty Mutual***

In 2016, the Supreme Court ruled that the Liberty Mutual insurance Company's health plan, a self-insured "employee welfare benefit plan" under ERISA, and its TPA, the Blue Cross Blue Shield of Massachusetts, were not required to comply with Vermont's law that mandated the submission of health care claims and other information to the state's APCD, stewarded by the Green Mountain Care Board. In a majority opinion delivered by Justice Kennedy, the Court found that "ERISA's express pre-emption clause requires invalidation of the Vermont reporting statute as applied to ERISA plans. The state statute imposes duties that are inconsistent with the central design of ERISA, which is to provide a single uniform national scheme for the administration of ERISA plans without interference from laws of the several States even when those laws, to a large extent, impose parallel requirements."<sup>259</sup> State-by-state regulations for self-insured plans, the Court noted, "could create wasteful administrative costs and threaten to subject plans to wide-ranging liability" and found that "preemption is necessary to prevent the States from imposing novel, inconsistent, and burdensome reporting requirements on plans."<sup>260</sup>

The Court also noted, however, that the “Secretary of Labor has authority to establish additional reporting and disclosure requirements for ERISA plans. ERISA permits the Secretary to use the data disclosed by plans ‘for statistical and research purposes, and [to] compile and publish such studies, analyses, reporting and surveys based thereon as he may deem appropriate,’” among other purposes, and “may be authorized to require ERISA plans to report data similar to that which Vermont seeks.” Justice Breyer expanded on the suggestion in his concurrence: “Pre-emption does not necessarily prevent Vermont or other States from obtaining the self-insured, ERISA-based health-plan information that they need. States wishing to obtain information can ask the Federal Government for appropriate approval.” Breyer cited the authority of the Secretary of Labor, as well as potentially the Secretary of HHS, to fulfill such requests. “I see no reason why the Secretary of Labor,” he continued, “could not develop reporting requirements that satisfy the States’ needs, including some State-specific requirements, as appropriate. Nor do I see why the Department could not delegate to a particular State the authority to obtain data related to that State, while also providing the data to the Federal Secretary for use by other States or at the federal level.”

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### **State Responses to *Gobeille***

After the *Gobeille* decision, states sought to regain access to ERISA-preempted self-insured data through four pathways: (1) by expanding on existing DOL “Form 5500” reporting to include self-insured membership and claims data, (2) by developing and proposing a national APCD “Common Data Layout” to the DOL for its blessing to use it to resume self-insured data collection (as suggested by Breyer), (3) through voluntary reporting by major employers, and (4) by compelling TPA submission by tying requirements to other state regulations.

#### **(1) Form 5500, Schedule J**

Under ERISA and the Internal Revenue Code, pension and other employee benefit plans—including self-insured health plans—are required to file annual “Form 5500” reports with the DOL that describe the plan’s financial conditions and operations. The reporting series serves as an “important compliance, research, and disclosure tool for the [DOL], a disclosure document for plan participants and beneficiaries, and a source of information and data for use by other Federal agencies, Congress, and the private sector in assessing employee benefit, tax, and economic trends and policies.”<sup>261</sup>

During the summer of 2016, the DOL proposed data collection and content revisions to its Form 5500 reporting that would build on previous technology and data-processing changes in 1999 and 2009. Proposed changes included:

- Expanding and modernizing financial and investment information reported by plans to reflect current market practices and oversight needs;
- Eliminating reporting loopholes for certain plans; and
- Aligning with new ACA requirements—Sections 2715A and 2717 of the PHSA and incorporated into ERISA Section 715—that require self-insured health plans and TPAs to report a “host of information on health plan enrollment and claims.”<sup>262</sup>

In a new “Schedule J,” self-insured health plans would be required to submit new aggregate data “about benefits and plan design characteristics; funding; grandfathered plan status; medical loss ratio rebates and other rebates received by the plan; service provider information; information on any stop-loss insurance; claims processing and payment information; wellness program information; and other compliance information.”<sup>263</sup> DOL sought public comments on the changes, including Schedule J, “in light of the Supreme Court’s recent decision in *Gobeille v. Liberty Mutual Insurance [Company]*.”

NASHP, NAHDO, and the APCD Council responded to the call for public comment, commenting that “Schedule J is insufficient to meet the goals under ERISA and the ACA of greater transparency and oversight of health care cost and quality—goals served by State data collection but imperiled by the *Gobeille*... decision.” The organizations proposed that the DOL:

Pursuant to its authority under PHSA §§ 2715A and 2717 and ERISA §§ 104 and 505, require as part of Schedule J that group health plans submit a standardized health care claims and related dataset (the ‘Common Data Layout’ [CDL]), to be tested through a pilot program in collaboration with States with APCD data collection capacity. The adoption of the Common Data Layout [a developing uniform state APCD layout at the time] will minimize cost and burden on ERISA plans and adhere to ERISA’s statutory goals of uniformity, consistent with the Supreme Court’s decision in *Gobeille*. To further reduce the burden on ERISA plans, all ERISA plan data, self-funded and fully-insured, could be submitted using the Common Data Layout...

Recognizing the technical and operational complexity of DOL building a system to collect health care claims data, we suggest that DOL pursue a pilot approach to test how partnering with State APCDs through cooperative agreements under ERISA § 506 can assist DOL with its oversight and analysis through Schedule J. The APCDs could annually report aggregated data drawn from the Common Data Layout to DOL as part of Schedule J reporting and analysis. Such a collaboration between DOL and State APCDs will minimize unnecessary duplication and expense and preserve the value of the substantial investment in state APCDs that was made through federal grants to states to develop these databases under PHSA § 2794.<sup>264</sup>

With the change in federal Administration at the start of 2017, the DOL ultimately made “some changes to the forms but did not go as far as requiring claims data to be submitted.”<sup>265</sup>

## (2) State APCD Common Data Layout (CDL)

After *Gobeille*, the APCD Council proactively convened states and payers to develop a state APCD CDL, a template for state APCD data file fields, formats, and layouts, with the hope that the uniform layout would be considered and blessed by DOL for use in the resumed collection of ERISA-preempted, self-insured data.<sup>266</sup> To create the CDL, “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. ... The first version of the CDL was published in December 2018,” and continues to be maintained and updated by the APCD Council.<sup>267</sup> The CDL was submitted to but never approved by the DOL as a uniform layout by which states could request self-insured data. As discussed in Section III.A, while many states share many elements of the CDL, few have implemented its guidance fully. However, the CDL was and continues to be cited as the proto standard by which future national self-insured data collection could occur—if it were further developed and more broadly implemented.

In 2021, the DOL’s convened SAPCDAC recommended that “the DOL should use the content of the APCD-CDL as the basis for the standard reporting format for submitting self-funded plan data to APCDs. The APCD-CDL is a good starting place for states, as it provides a standard set of data elements that can be readily used today.”<sup>268</sup> The SAPCDAC further recommended that the CDL be enhanced to include “variables needed to capture the totality of payments to providers” (i.e., non-claims-based payments) and a “detailed data dictionary,” and that the DOL “should identify an ongoing [multi-stakeholder] stewarding body to maintain and update the uniform data layout,” potentially leveraging the existing experience and processes of standard development organizations (SDOs).

## (3) Voluntary Data Collection

Following *Gobeille*, many APCD states worked closely with their major employers and employer associations to encourage them to work with their TPA to “opt in” to submitting their data to the state’s APCD. Colorado, Massachusetts, New Hampshire, and Utah, among other states, all created voluntary data submission guidance and processes to support such collection, to mixed effect.<sup>269</sup> One report noted from its interviews that while “some large employers, particularly those that have an institutional connection to the APCD mission like health systems or universities, do opt in to data-sharing with state APCDs ... these efforts have borne limited fruit, and data collection from non-governmental self-insured plans is fairly limited and non-repetitive.”<sup>270</sup>

APCD states have experienced strong headwinds in their attempts to solicit submissions, including:

- Lack of understanding among employers about what APCDs are, their value, and how data submission could benefit them;
- State variation in the process by which an employer can choose to opt-in (i.e., an employer working in multiple states may need to “opt-in” to each state APCD using a different method);
- Concern about their potential legal liability of “voluntarily” sharing employee/member plan data; and
- The commanding role of the TPA, as a health benefit plan manager, administrator, and advisor to the employer, which may have a financial or business interest in the employer not submitting data and/or may charge the employer for the option to submit data.<sup>271</sup>

Colorado's CIVHC invested heavily in such efforts, working with purchasing alliances, their local business group on health, Chambers of Commerce, and directly with major employers to encourage submission.<sup>272</sup> CIVHC developed standard employer reports and established new use cases to demonstrate the value of data submission, released a legal opinion on what voluntarily submitting data to its APCD would and would not mean for employer liability, and created standard, easy to understand, "opt-in" forms, business associate agreements for the TPA/Administrative Services Only (ASO), and data sharing agreements for regular use.<sup>273</sup> Despite these efforts, however, CIVHC still found significant resistance to reporting, not from the employers with which it was engaging, but from employers' TPAs/ASOs, which had "contracts prohibiting [data] submission to APCDs, [citing] covered entity/HIPAA privacy concerns" and established financial barriers to employer submission, "charging excessive per member per month fees," should employers wish to submit data. These barriers pushed CIVHC to consider more compulsory methods to incent data submission.

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#### (4) Attempts at Required Data Submission

In an attempt to "level the playing field for ERISA-covered entities and remove barriers preventing them from taking advantage of the option to submit to the CO APCD," CIVHC sought to "require that payers [many of which also serve as ASOs for self-funded plans] already submitting data to the CO APCD must allow ERISA self-funded employers to voluntarily opt-in to APCD submissions at no additional cost."<sup>274</sup> The proposal failed, meeting "significant resistance from payers." The proposed sub-regulatory data guidance change was not able to withstand pushback without a state regulatory enforcement mechanism over payers working in an ASO capacity and TPAs, and was withdrawn.

Other states have similarly sought to leverage existing state regulatory authority to compel TPAs to submit data to state APCDs, to significant resistance and little success. In 2021, members of the Georgia Senate introduced a bill (Senate Bill 1), that would have required "entities that receive certain [state] tax credits [or that are otherwise contracted with the state to provide health care coverage or services, and] that provide self-funded, employer sponsored health insurance plans" to submit self-insured data to the state's in-development APCD.<sup>275</sup> The bill failed to leave committee after facing industry protest.

ERIC, a national advocate for ERISA protections and a frequent voice in state APCD discussions, wrote to the committee "in strong opposition of SB 1."<sup>276</sup> ERIC argued that the bill violated the *Gobeille* ruling of ERISA preemption, while advancing a position that the DOL's charge of the SAPCDAC to identify a "reporting format that enables voluntary participation in state APCDs by ERISA plans" was confirmational of the limits of states' authority to collect this data (potentially implying limits to DOL's authority to allow states to collect this data directly). "The legislation Congress passed in December of 2020 tasked the federal government with creating



a uniform, national framework for ERISA plans to voluntarily participate in state APCDs” (emphasis added), ERIC’s letter stated, before calling for delay of the bill until the SAPCDAC process concluded. ERIC further noted that it and its “member companies would consider filing suit to invalidate” any law passed.

### Key Employer and Industry Positions

Understanding the concerns of and productively engaging industry groups that represent self-insured employers will be essential to developing sustainable national health system data capacity for the public good. ERIC, the American Benefits Council, and the PBGH are among the larger and more vocal employer industry groups tracking and participating in APCD discussions nationally.

In 2021, an ERIC representative testified before the SAPCDAC, arguing against the Committee’s consideration of an “opt out” provision for self-insured employers.<sup>277</sup> Per meeting notes, ERIC’s representative “stated that ERIC’s position is that a requirement with an opt out is still a mandate ... [and] ERIC would sue if the DOL used the opt-out [model].” However, the ERIC representative also shared insight into what model the association may be in favor of, a potential road map for future, productive public-private sector discussions. Per meeting notes, ERIC commented that its:

Raison d’etre is protecting national uniformity of ERISA plans, and to enable member companies to provide the best benefits possible. Most members have employees in every state, so even a minor requirement for each can turn into a major issue if this requirement differs a little in each state, so even though they understand APCDs help lower health care costs, they cannot be subject to different regulations in every state. Members’ shared goals led to ERIC’s endorsement of centralized data capture for health care data, if there were one point of contact, one process, and one timeline used. ... He stated that instead of concentrating on opt-outs, the Committee should create a complete framework for self-funded plans to provide all their data. Meanwhile, ERIC would continue advocating for one streamlined method of submitting this data.

However, it is unclear whether this is the official position of the association. Previously, in response to the DOL’s prior Form 5500 Schedule J proposal, ERIC posited that in *Gobeille*, the Supreme Court

Invalidated a state data collection requirement that would have imposed claims reporting upon self-insured ERISA plans operating within the state of Vermont. In no way did this decision compel or empower the federal government to increase reporting requirements; in fact, SCOTUS affirmed that government entities must have specific statutory authority to demand detailed information reporting from plan sponsors regarding their health claims data. If there is to be a federally-run all-payers health claims database, that database will require specific legislative authorization, which will necessarily include details relating to what must be reported, to whom, by whom, when, and in what format. All of these determinations require congressional action and, as such, are at this time outside of the authority of the Departments to make.<sup>278</sup>

ERIC's 2016 statement may indicate that its position is that executive agencies—or the SAPCDAC—do not have the authority to require the reporting of detailed information from self-insured plans. Particularly in light of the Supreme Court's recent *West Virginia* decision, it will be important that federal regulatory agencies carefully consider this position in any executive-led pursuit of a national APCD.<sup>279</sup>

The American Benefits Council, a "national nonprofit organization dedicated to protecting employer-sponsored benefit plans ... [and which] represents more major employers ... than any other association that exclusively advocates on the full range of employee benefit issues," offered a similar position in its response to the SAPCDAC's recommendations.<sup>280</sup> The ABC stated:

We appreciate the policy goals behind APCDs—that is, increased cost and quality transparency as a way to bring about higher-quality, lower-cost health care. The Council has long supported increased price and quality transparency and access to data for employer plan sponsors as a means to address health care costs. Employers play a critical role in the health care system, leveraging purchasing power, market efficiencies, and plan design innovations to provide health coverage to millions of Americans. Most employers that have had success decreasing the rate of health care spending have started by analyzing their data. Employers do this to better understand how much they are spending for various services delivered in different settings and, ultimately, to steer their enrollees to higher-value providers operating in higher-value settings. More recently, we have seen employers make efforts to seek and use plan data to address health plan inequities and social determinants of health, and we have supported policies to further achieve these goals.

We also note that the Council has taken the position that access to claims and related data will assist all stakeholders in making more informed utilization and plan design decisions and, accordingly, **we have generally been supportive of the establishment of an APCD at the federal level.** In the context of various legislative efforts, **we have expressed to Congress** that a properly crafted database that minimizes the burden on self-insured group health plans could be a helpful tool in employer efforts to drive lower-cost, higher-quality health care. At the same time, we have strongly recommended that policymakers prevent the burdens and costs associated with conflicting state requirements that arise from any mandates for reporting to state APCDs. ...

Employers will need sufficient information to understand the benefits of potentially reporting to state APCDs, including whether they and other stakeholders will have access to the data in the APCD and how the state plans to use the data for its own purposes. In this vein, the Committee recommended that DOL clarify and emphasize the public policy and business interests of self-insured plans voluntarily reporting to state APCDs, including through communications to plans or a public policy statement and that DOL convene a roundtable of self-insured plans or publish a white paper on the benefits of state APCDs. We appreciate these recommendations by the Committee and note that we are happy to continue to work with DOL on these efforts, to the extent helpful." (Emphasis added.)

The Council offers support for the establishment of a federal-level APCD but quickly notes its “express[ions] to Congress” on the values of a “properly crafted database.”

The Council’s support of a national APCD was previously expressed as part of its joint “Consumers First” advocacy letter to the HELP in response to the LHCC Act.<sup>281</sup> The letter—jointly signed by the Council, PBGH, Families USA, the American Academy of Family Physicians, the American Federation of State, County and Municipal Employees, and the First Focus Campaign for Children—shared explicit support for the establishment of a national APCD by a “nongovernmental, not-for-profit organization.” It further advocated that “users of the information—especially physicians and consumers—have a key role in governance.” These suggestions, in addition to ERIC’s reasoned and reasonable position, were considered in the development of this paper’s proposal.

### The Question of Executive Authority

In its final report, the SAPCDAC recommended that the DOL implement its proposals to incent the voluntary opt-in reporting of self-insured data by employers to state APCDs and measure its success. Should voluntary self-insured data reporting not increase over a period of time (e.g., three years), the SAPCDAC advised DOL to pursue either:

Administrative action or [make] a recommendation for Congressional action to require uniform standards for submission and mandatory submission across group health plans, government sponsored insurance, and fully insured plans; or

Action by DOL in its oversight role to centrally collect all claims data from self-insured employers that would be disseminated to states based on beneficiary geography (residence and utilization of health care services), while states continue to collect all other data.<sup>282</sup>

The question of federal executive authority to mandate the collection of this data—while explicitly noted in *Gobeille*—is foundational to the SAPCDAC’s proposals but has not been settled legally or in the public discourse. While industry groups have challenged executive authority in this area, other analyses and recently implemented federal actions have supported it.

In a 2019 paper by the University of California, Hastings, the authors highlighted several authorities the executive branch and its agencies could leverage immediately to support self-insured data collection:

To require ERISA plans to report health care and drug utilization and price information, the [DOL] could independently create federal regulations governing health care transparency, or it could work with state or private entities to coordinate those efforts. To do so, **the [DOL] could use its existing authority under the [ACA] and ERISA to require self-funded health plans and their administrators to report a standardized set of data about health care claims and drug pricing to the [DOL]. The statutory authority for the [DOL] to require ERISA plans to submit health care claims data derives from Public Health Service Act (PHSA) § 2715A, which authorizes collection of data on health care costs and payments, and PHSA § 2717, which authorizes collection of data on health care quality.** Both provisions were among those health insurance reforms created by the ACA and applied to group health plans by ERISA

§ 715. In addition, the [DOL] has authority to collect data under the provisions of ERISA §§ 104 and 505, which authorize [it] to promulgate regulations and require any information or data from plans as necessary to carry out the purposes of the statute.<sup>283</sup> (Emphasis added.)

The authors, however, did note a key operational barrier to implementing such collection: even if the DOL exercised its authority to collect the data, it “may lack the resources necessary to collect, store, analyze, [and] distribute the information to states, policymakers, and researchers.” They suggested that under ERISA Section 506, the DOL could alternatively partner with states or private entities to redirect the collection and distribution of this data nationally. They also proposed a concept that the DOL “could require ERISA plans to report such data to a state-run APCD or to a private entity contracted to perform the functions of an APCD for states without an APCD, similar to the federal exchanges under the ACA,” a concept leveraged, in combination with others, in this paper’s recommendations.

Coincidentally, under the same CAA that established the SAPCDAC, Congress also passed broad new health care spending reporting requirements—and data collection authorities—for self-insured health plans to allow policymakers “data to make informed decisions” in support of market competition.<sup>284</sup> CAA Section 204 mandated new annual prescription drug data collection (RxDC) reporting for insurance companies and employer-based health plans.<sup>285</sup> Starting in late 2022—after COVID-19-related implementation delays—self-insured plans will be responsible for submitting “information about prescription drugs and health care spending” to HHS, DOL, and the Department of the Treasury. While agencies revised proposed rules for collecting more granular, plan-level data to address “privacy concerns” raised by stakeholders in public comments, they did reserve the right to revisit the decision:

The Departments are of the view that, at this time, the clear benefits of the aggregate data approach outweigh the potential drawbacks. However, the Departments solicit comment on the general use and the specific aspects of this data aggregation approach versus a plan-specific data collection approach. In addition, after the Departments begin to receive section 204 data submissions and have the opportunity to evaluate the efficacy and adequacy of the aggregate data approach, the Departments will further review and analyze the merits of this approach and may modify the approach in future rulemaking if necessary or appropriate.

Further, and relevant for the proposals later put forth in this paper, Section 204 also required reporting of federally administered health plans, including those contracted by the OPM to support the FEHB Program.<sup>286</sup>

Should an executive agency seek to leverage existing authorities to create a national APCD, it should anticipate challenges to those authorities, particularly in the wake of *EPA vs. West Virginia*, wherein the Supreme Court advanced a narrowed view of agency regulatory authority.<sup>287</sup>

### **Potential Solution Strategies**

Stakeholders can pursue several strategies to address the ERISA-preempted, self-insured data gap.

#### **(1) Advance a uniform national APCD data standard to support self-insured data collection by states:**

The DOL, in partnership with HHS, should procure an SDO to support a newly established National APCD Standards Advisory Group (APCD SAG) to establish a national APCD data standard<sup>288</sup> that builds from the CDL (see callout), and reflects current industry transaction and coding standards as well as the analytic needs

of data users.<sup>289</sup> The APCD SAG should have representation from federal representatives responsible for overseeing ERISA and related data collection (i.e., DOL, HHS); state APCD representatives; prospective data submitters, including payers, TPAs, and Medicaid agencies; consumer privacy advocates; and prospective data users (e.g., academic researchers, purchasers, federal and state regulators). The APCD SAG, with the support of the SDO, should be charged with establishing a draft national APCD standard within one year of its first meeting and submitting it to the governance body of any National HDO (if established) for review and approval, then DOL for review, preliminary approval, publication and public comment. Following public comment, the APCD SAG, supported by the SDO, should recommend any revisions to the standard to the National HDO governance body and DOL within three months of the close of public comment for the standard to then be reviewed and adopted by the DOL as the national data standard by which states may collect administrative data from ERISA-preempted self-insured plans. The national APCD standard will include standards by which state APCDs will collect data across all payer types and lines-of-business (see Solution Strategies for Opportunity #3.1 for further discussion of concurrent standardization benefits, and the role of a National HDO in overseeing the standard after it is established).

Concurrent with the development of the national APCD data standard, the APCD SAG, in coordination with the National Committee on Vital and Health Statistics (NCVHS) and supported by the SDO, should propose to the National HDO governance body, then DOL, the process by which the national APCD data standard should be governed after establishment. Any data standards governance process should be transparent and open to feedback from the public and all stakeholder groups. The process should include ongoing representation from all groups involved with the establishment of the initial standard; it should include an expedited review and approval process for the addition of state classification codes within existing data fields.<sup>290</sup>

The national APCD standards development process would likely need to be started by federal leaders, providing assurance that it would result in the ability to collect ERISA-preempted, self-insured data, but may otherwise be funded or supported by philanthropic organizations and payers. For more detail on motivating factors and barriers to standardization, see [Opportunity #3.1](#) and its discussion of the “[The State APCD ‘Prisoner’s \(Data\) Dilemma’](#).”

### Building from the APCD-CDL

A National APCD data standard can build from APCD-CDL, an invaluable product of the APCD Council, NAHDO, and numerous volunteer state APCD leaders.<sup>291</sup> As one reviewer noted, the CDL has been an effective data layout, minimizing APCD specification variation by serving as a starting template for new APCDs, but “it was not created through the usual standards-setting processes,” which would be necessary to support any formal national data standards compact. Engaging an SDO—and payers, as expert advisors—in the CDL’s further development would allow for the creation of more detailed, rigorous, and “necessary data dictionaries, guidelines, and other appropriate standards” (e.g., transmission practices, coding standards). As similarly noted by the SAPCDAC, to serve as a national APCD standard, the CDL would need to be “enhanced to reflect the data needs of all APCD states... include complete field-level classification definitions and detailed instructions on data submission... [and] be supported by a governing body to manage submission changes on a predictable basis.”<sup>292</sup>

### **(2) Confirm DOL authority to set a national standard for ERISA-preempted self-insured data and require reporting to state or national APCDs:**

The DOL should be prepared to publicly confirm its authority to promulgate a national standard for the collection of ERISA-governed self-insured data and require its reporting to state or national APCDs under PHSa Section 2715A, PHSa Section 2717, ERISA Section 715, as well as ERISA Sections 104 and 505 and statutes represented in the original *Gobeille* decision. If DOL determines its authority to collect this data is somehow unclear, it should work with congressional leaders to reaffirm its authority to meaningfully oversee and regulate—what may otherwise be considered—an industry responsible for providing health care coverage for nearly a third of Americans by offering a clerical amendment to ERISA.

**(3) Prohibit payer/TPA submission fees:** The DOL, in partnership with HHS, should use their regulatory and contractual authorities to ensure that payers and TPAs do not engage in prohibitive “information blocking” activities, such as charging fees to self-insured employers for the submission of their data to state APCDs or a national HDO.<sup>293</sup>

**(4) Set federal-state terms of data collection:** In acknowledgment of the significant administrative burden confronted by APCD data submitters (payers, TPAs), the data privacy risks of unnecessarily duplicative health data exchange, and the value of self-insured data to states, the federal government should work in partnership with states to share the terms by which it may allow otherwise ERISA-preempted self-insured data collection (potentially in coordination with eligibility of federal funding and other federal data access). Federal and state partners may agree to further harmonization in data collection practices, data access requirements, or specific models of national data collection that could offer efficiencies for data submitters (i.e., a single submission target at a national HDO). Industry input should be solicited, publicly heard, and carefully considered in such deliberations.

## #2.2: Resolve Barriers to Federal Data Collection

State APCDs also frequently lack data for **individuals receiving health care coverage and services through federally administered programs**. Most acutely, many state APCDs still consistently lack integrated Medicare FFS (i.e., Parts A and/or B) data—which provides coverage for nearly 38 million Americans—as part of their databases, limiting use for valuable use cases in support of America’s graying population (e.g., dual-eligible analyses).<sup>294</sup> State APCDs also lack data for individuals receiving services through the:

- FEHB Program, which covers approximately 8 million individuals;
- VHA, CHAMPVA, and TRICARE, which cover approximately 11.7 million individuals; and
- IHS, which provides health care services for an eligible population of approximately 2.6 million individuals.

While these populations comprise a relatively small percentage of insured lives nationally, their absence can have a significant impact on states where these populations are disproportionately large (e.g., Virginia and federal employees) and can limit APCDs’ utility for important and timely use cases (e.g., health equity analyses).

Finally, many state APCD agencies continue to face resistance to their collection of **health care claims data for SUD treatment services**, due to perceived 42 CFR Part 2 protections, despite the Substance Abuse and Mental Health Services Administration’s (SAMHSA) 2020 clarification that:

Federal, state and local governmental agencies and third-party payers may conduct audits and evaluations to identify needed actions at the agency or payer level to improve care; that audits and evaluations may include reviews of appropriateness of medical care, medical necessity, and utilization of services ... Section 2.53 also ... allows for patient identifying information to be disclosed to federal, state, or local government agencies, and to their contractors, subcontractors, and legal representatives[,] for audit and evaluations required by statute or regulation.<sup>295</sup>

SAMHSA has yet to explicitly clarify state APCD eligibility to receive this information.<sup>296</sup> Having access to federally funded SUD treatment service data is critical for state APCDs to be used to understand the health and health-related challenges confronting their states’ populations and to inform state policymaking and program actions seeking to stem the opioid epidemic.<sup>297</sup>

States are limited in the actions they can directly take to address these critical data gaps without corresponding federal responses.

### Potential Solution Strategies

Stakeholders can pursue several strategies to address these federal data collection barriers.

**(1) Establish federal or national centralized data clearinghouse for federal claims/encounter data:** Similar to the bill proposed by Congressman Beyer in 2020,<sup>298</sup> whether as part of a national APCD or a federal data access gateway, federal agencies can develop a centralized pathway for states and researchers to access market claims and encounter data for federally administered programs. This program may build upon CMS' existing QE process that provides many state HDOs with access to Medicare data<sup>299</sup> to also include data for the FEHB Program,<sup>300</sup> TRICARE,<sup>301</sup> CHAMPVA, VHA, and IHS. The federal government or national HDO may choose to engage in data-sharing reciprocity with states, sharing this information—potentially in addition to permitting ERISA-preempted self-insured data collection—in exchange for state APCD data.

**(2) Issue federal guidance clarifying state APCD authority to collect SUD treatment information:** SAMHSA should offer clarifying follow-up guidance to that issued on July 15, 2020,<sup>302</sup> explicitly stating that state APCD agencies may lawfully receive Part 2 SUD treatment claims data for specified purposes or provide clear guidance to states on what prerequisite protections (e.g., de-identification, data access restrictions) states must demonstrate in order to receive this critical—and potentially lifesaving—information in accordance with federal law.



### #2.3: Enhance State APCD Collection to Reflect Market Needs

**State APCDs are both empowered and limited by the data they comprise.** An APCD's utility decreases to the extent that the membership, claims and encounter data, or provider information it is provided with are not complete, accurate, or reflective of market operations. States can enhance the utility of the APCD data they receive by: instituting rigorous data quality checks with active feedback loops; advancing new data reporting requirements; elevating data quality standards; imputing missing data or developing proxies for missing information; and holding submitters publicly accountable for the data they submit. Data quality increases the more users understand the intent of its use, the more the data is publicly used, and whenever the data is tied to payment.

The usefulness of state APCD data may be nascent or limited in specific areas including, but not limited to:<sup>303</sup>

**(1) Non-claims-based payments:** Non-claims-based payments are “payments that are made for something other than a FFS claim. Non-claims-based payments can be based on historical claims data, but they are not paid on a FFS claims basis.”<sup>304</sup> As the health care market increasingly shifts from transaction-based payments to outcome-influenced payments (i.e., APMs), the payment amounts reflected on traditional claims/encounters—and included in an APCD—may not be reflective of the final payment received by a delegated payer or provider. Examples of non-claims-based financial transactions include, but are not limited to:

- Capitation Payments
- Care Management/Care Coordination/Population Health Payments
- Electronic Health Records/Health Information Technology Infrastructure/Other Data Analytics Payments
- Global Budget Payments
- Patient-centered Medical Home Payments
- Pay-for-performance (P4P) Payments
- Pay-for-reporting (P4R) Payments
- Primary Care and Behavioral Health Integration Payments
- Prospective Case Rate Payments
- Prospective Episode-based Payments
- Provider Salary Payments
- Retrospective/Prospective Incentive Payments
- Risk-based Payments
- Shared-risk Recoupments
- Shared-savings Distributions<sup>305</sup>

There is currently no standard for the collection of this information nor any cross-state agreement in what defines a non-claims-based payment. Several state APCD agencies have individually pursued the collection of data on the rate of APM adoption and/or non-claims-based payment amounts to address this data gap, including:

- Oregon’s OHA, which started collecting a Payment Arrangement File in 2021, reflecting contracted financial risk-sharing arrangements between payers and providers;<sup>306</sup>
- Colorado’s CIVHC, which started collecting data on APM adoption with its primary care reporting in 2019, broadening data collection to its market collections in 2020;<sup>307</sup> and
- MHDO, which is required by a new law to collect non-claims-based payment for behavioral health.<sup>308</sup>

Understanding the extent of health care transactions covered under APMs, and the level of risk-sharing involved in those payments is critical information not only to continue to buttress APCDs’ payment data fields’ existing value but also to provide state policymakers and regulators with new, valuable information about the financial risks borne by health care organizations in their states, and conversely, how critical provider types (e.g., primary care providers, behavioral health providers) are being financially sustained.<sup>309</sup>

**(2) Demographic data collection:** Payers collect a range of demographic information about their members, including race, ethnicity, preferred language, and disability status (“REaL” data), and many payers are exploring—or being required to solicit—data on member sexual orientation and gender identity (“SOGI” data) to ensure their membership is being equitably supported by the health care system.<sup>310</sup> These demographic variables are invaluable to equity-focused health system oversight, and population and public health analyses and use cases—when these data are populated using a common standard by payers, which they often are not.<sup>311</sup> In 2019, NAHDO assessed the completeness of race and ethnicity data in five states’ APCDs and found that usable data for race ranged from 13% to 44% among states, and usable data for ethnicity, between 0% and 35%.<sup>312</sup> While state APCD agencies are not able to directly impact the completeness of payer-submitted data, which is a byproduct of market financial incentives for the payer and the maturity of payer processes for collecting this information from members, they may be able to impact the:

- Demand for this information by data users;
- Quality of the supply of this information from data submitters (payers); and
- Availability of indicators of race and ethnicity.

State APCD agencies have the opportunity to play similar roles, facilitating the collection, imputation, and use of SDOH information as well.<sup>313</sup>

## Potential Solution Strategies

Potential strategies to address these challenges include:

**(1) Develop non-claims-based payment data standards:** As recommended by the SAPCDAC, state APCD agencies should collaboratively—potentially in partnership with DOL—“determine what additional high priority [non-claims-based] data elements should be contained in data submissions to APCDs and create standards and a process for submitting such data. Health plans could submit data on non-claims-based payments in a separate [APCD] file.”<sup>314</sup> The Milbank Memorial Fund further defines the need, recommending that:

Each state should create a technical advisory group or groups comprising state officials, analysts, insurers, and providers. States with operational all-payer claims databases (APCDs) should be sure to include analysts involved in both claims-based and non-claims-based data reporting in the advisory group. Technical advisory groups can assist states in implementing the recommended measurement approach, developing a process for collecting and validating data from payers, and creating alignment between primary care spending efforts and other statewide efforts (e.g., cost growth target programs). These groups can also facilitate documentation of how states have categorized certain types of payments to ensure consistency in intra-state and cross-state comparisons. States should be encouraged to publicize their decision-making rationale and provide specificity and guidance for payers.<sup>315</sup>

State APCD agencies may be supported by philanthropic funding to convene around the need and to develop a common approach for resolving it.

**(2) State APCD agencies can serve as state data conveners and solution developers:** State APCD agencies, as centralized HDO, are uniquely positioned to serve as health data conveners for public and private sector data collectors and users in their states. They may leverage this position to:

- Highlight the value of certain data or data uses to advance public and private goals and objectives, and—where necessary—spotlight data gaps that public and private stakeholders can work together to resolve.
- Support statewide discussions about data standardization, helping public agencies harmonize requirements for key and common fields of interest (e.g., race, ethnicity), and potentially represent public sector responses to federal health data Requests for Information (RFIs).
- Develop proxy measures for data users where needed data is not available. For example, absent reliable and complete race and ethnicity data—and SDOH data—state APCDs have leveraged the geographic data they have available to estimate indicators for this missing data.<sup>316</sup> To the extent state APCD agencies serve as HDOs for the state, stewarding multiple data resources, they may also be able to employ indirect characteristic attributions to member data (i.e., complete data from one data set by linking data to it from another data set, to the extent federal and state law allow).<sup>317</sup>

State APCD agencies have the potential to serve as changemakers for their own data limitations, improving data collection, data quality, and data use for all stakeholders.

## Opportunity #3: Support State APCD Data Collection, Access, and Analytic Alignment

As individual state data resources, state APCDs were not designed to collect, curate, and make data accessible to users in the same way. Heterogeneity in how data users can access state APCD data, and what data they get once accessed, creates barriers to cross-state and regional analyses, and limits state APCDs' individual and collective utility for broader use cases and impact.

### #3.1: Support APCD Data Standardization to Reduce Burden on Payers and States

The lack of state APCD data standardization creates significant administrative burden for payers and for states. Payers and states must grapple with a lack of industry data standards for analytic data reporting, an issue compounded for payers as each state collects APCD data using slightly different specifications. States, meanwhile, confront significant challenges in normalizing the payer data they receive, even when their guidance is followed, as each payer has different processes for versioning and adjudicating claims.

#### Payer & State Challenge: Missing Industry Data Standards

There is no comprehensive, industry data standard for APCD data (i.e., analytic data). The lack of a standard requires states to create ad hoc, analytically-oriented data fields necessary for APCD use. States may design these fields in different ways.

Nationally, payers collect, curate, and exchange claims data in accordance with a wide array of data format, transaction, and coding standards, as required of them by federal and state laws and regulations (e.g., HIPAA), federal regulators (e.g., ONC, CMS), and payer and industry contracts. Standards include, but are not limited to:

- American National Standards Institute (ANSI) [X12 Accredited Standards Committee](#) (ASC) standards for the processing and billing of medical claims, including for the:
  - 834 (member benefit enrollment and maintenance);
  - 837I/P (health care claim);
  - 270/271 (eligibility and benefit inquiry and response); and
  - Post Adjudicated Claims Data Reporting (PACDR) Files;<sup>318,319,320,321</sup>
- National Council for Prescription Drug Programs (NC PDP) standards for the processing and billing of retail pharmacy claims; and
- Codes and terminologies for diagnoses, procedures, and billing, including the:
  - ICD-10;
  - Current Procedure Terminology (CPT), and related Health Care Common Procedure Coding System (HCPCS);
  - Code on Dental Procedures and Nomenclature (CDT);
  - National Drug Codes (NDC); and
  - Uniform Billing (UB) 04 and Health Care Finance Administration (HCFA) 1500 requirements maintained by the National Uniform Billing Committee (NUBC) and National Uniform Claim Committee (NUCC).<sup>322</sup>

Standards are managed by various DSMOs and governance processes, which payers must monitor for changes to maintain regulatory and contractual compliance in their course of doing business.

However, analytic data needs are different than data required for transaction purposes. State APCDs require fields like submitter codes, submission dates, coverage flags, record types, plan/benefit information, and state-specific fields (e.g., ACO identifiers, public employer indicators) to support meaningful analytics, which are not present—or needed—in transaction-oriented data, as standardized in ANSI ASC x12N 834, 837, or 271 file formats.<sup>323</sup>

The differences are not always small. By one payer’s analysis, using the APCD-CDL as a proxy for a typical state’s APCD submission requirements, approximately:

- Two-thirds of the Member Eligibility File fields were not aligned with ANSI ASC x12N 834 and 271 standards;
- Of the Medical Claims File fields, 14% were not aligned with the ANSI ASC x12 PACDR standards;
- Of the Dental Claims File fields, 18% were not aligned with the ANSI ASC x12 PACDR standards;
- Of the Pharmacy Claims File fields, 25% were not in the NCPDP standards; and
- Over 90% of the Provider File fields were not aligned with a parallel ASC x12 reference.<sup>324</sup>

While other knowledgeable reviewers of this paper noted these estimated differences—especially for the Member Eligibility File—to be high, all noted that the lack of one-to-one matching to EDI transaction standards is not surprising, and to be expected, given the different purposes of data use. “There will always be data fields in an APCD that do not align with x12,” one reviewer noted. “A [national] CDL would help” both payers and states, another submitted.

### **Payer Challenge: Lack of Cross-State APCD Data Uniformity**

State APCDs do not consistently collect data using a common, uniform data specification—nor do they always collect data in accordance with industry standards, when available. The APCD CDL frequently serves as a template or model for state APCD data guidance design, organically resulting in similar state APCD file layouts and a “common core” of data fields across states, but most states deviate from its guidance in ways big (e.g., frequency of file delivery, differences to file structure) and small (e.g., including different classifications within data fields).

As discussed previously (see Section III.A), state APCD submission requirements can vary from five to nine different files,<sup>325</sup> with different submission frequencies (e.g., monthly, quarterly, and annually), and differences in what data they require submission for (e.g., denied claims).<sup>326</sup>

State APCDs differ in what data they collect and how they collect it. For example, Oregon’s APAC, in its Member Eligibility File, requests member plan information like Health Insurance Oversight System (HIOS) ID and medical home flags; CIVHC/Colorado’s APCD does not.<sup>327</sup> CIVHC/Colorado’s APCD requests an ERISA indicator flag and an NAIC identifier; Oregon’s APAC does not. CIVHC collects premium information in its APCD’s Member Eligibility File; Oregon’s APAC collects premium information in a separate Subscriber Billing Premium File. Both states request indicators of whether plans are part of state-specific programs.

Further, state APCDs may solicit different data in similarly named fields. For example, the MA APCD has over a dozen classifications of “Market Category Codes” for members based on the sponsoring-employer characteristics, the AR APCD has a consolidated five (Exhibit 15).<sup>328</sup> Conversely, while the MA APCD has only four classifications of “Member Language Preference,” the AR APCD reports to allow over 300 options.

**Exhibit 15: APCD Plan Member Data Collection Variation (for Illustrative Purposes)**

Market Category Code				Member Language Preference			
Massachusetts (Member Eligibility File: ME030)		Arkansas (Member Enrollment File: ME030)		Massachusetts (Member Eligibility File: ME033)		Arkansas (Member Enrollment File: ME030—sample)	
IND	Individuals (non-group)	IND	Individuals (non-group)	600	English	625, 627, 628	Spanish
ISCO	Individuals as a senior care option	LRG	Large employer/group	625	Spanish	620–622, 624	French
FCH	Individuals on a franchise basis	SMG	Small group/employer	997	Other Language	619	Italian
GCV	Individuals as group conversion policies	FGP	Federal government plan	999	Unknown/Not Specified	629–630	Portuguese
GS1	Employers having exactly 1 employee	GPL	State government plan			607, 613	German
GS2	Employers having 2 thru 9 employees					609	Yiddish
GS3	Employers having 10 thru 25 employees					708–715	Chinese
GS4	Employers having 26 thru 50 employees					720	Thai
GLG1	Employers having 51 thru 100 employees					728	Vietnamese
GLG2	Employers having 101 thru 250 employees					864	Navajo
GLG3	Employers having 251 thru 500 employees					800–863, 865–955, 959–966, 977–982	Other Native American languages
GLG4	Employers having more than 500 employees					780–799	African languages
GSA	Small employers through a qualified association trust					Coding requested in alignment with U.S. Census Bureau 2012 Language groups	
OTH	Other types of entities. Insurers using this market code shall obtain prior approval.						



\*Data is requested and errors are reported, but will not cause a file to fail.

State APCDs are established to support local health data needs, and accordingly, their agencies request data in a format and method to best meet those needs. Presently, there is little incentive for states to strengthen alignment in what data they collect and how they collect it, especially as a process to harmonize data across states would be costly, time-consuming, and disruptive to existing payer reporting relationships without a clear and definitive value proposition (see “The State APCD ‘Prisoner’s (Data) Dilemma”).

The administrative and financial burden that state APCD reporting differences place on payers can be substantial, particularly for smaller, regional payers and payers who have not previously submitted to a state APCD. Submitting data to a state APCD is also not a one-off activity, but rather an ongoing process that must be managed. Payers needing to comply with multiple states’ APCD submission requirements must track

state-by-state specification changes in perpetuity and continually update their internal administrative data mapping—itself continually modified to maintain federal and state transaction compliance—to those being requested by each state APCD.<sup>329</sup> According to testimony by UnitedHealthcare to the SAPCDAC:

“The failure of states to adopt uniform data standards results in operational complexity and higher operating costs” of approximately \$1 million “to establish a state APCD data sharing platform” and “continuing annual expenditures of several hundred thousand dollars per state APCD depending on the amount of data and frequency of reporting.”<sup>330</sup>

Translating data from standard transactional formats or natively curated fields into state APCD formats can impact the quality of the data state APCDs receive, especially where state requirements are unclear or if there is not an exact one-to-one mapping with data in payers’ administrative data systems, requiring the creation of new information and potentially risking translation errors.<sup>331</sup> This concern only compounds as payers submit data to an increasing number of APCDs, each employing different reporting specifications.

Data users, particularly researchers pursuing multi-state analyses, must educate themselves on each state APCD’s data collection methods, file structures, and field formats—and navigate each state’s data access and transmission requirements (see later sections)—to effectively access, link, and analyze files, requiring a significant commitment of time and resources.

### **State Challenge: Payer Claims Data Differences**

State APCDs need to work with payers to harmonize the data they receive, which can look very different payer to payer, even when state data specifications are followed. Each payer has its own way of processing claims, and may be translating data from different fields internally to match state needs, especially when state APCDs are not following industry standard formats or industry standard formats are not available.

For example, payers differ in how they individually manage, track, and “version” claims as part of their adjudication processes, resulting in APCD submissions that—even when meeting state requirements—do not look alike. Some payers may manage claims adjudication by using “back out” claims with negative values, which, if submitted to an APCD and not consolidated with the original claim, could undermine any analysis using the data; other payers, however, may simply generate a new “version” of a claim with the revised amount, which can also impact claims-based analyses if submitted and not properly deduplicated with the original claim. The process of understanding payer versioning and ensuring APCD data collection and/or curation practices address variation in versioning (and other “local” coding) practices is critical to ensuring APCD data usability and conformity. Establishing such an understanding and developing processes to address natural payer data variation can take significant state and payer staff time and ongoing attention.

### **The State APCD “Prisoner’s (Data) Dilemma”**

State APCD agencies—and the payers that are required to report to them—are captured in a “Prisoner’s Dilemma,” wherein states, acting in their own self-interests, do not produce the optimal outcome.

Presently, each state APCD agency is requesting and receiving data from payers that represents a majority, but not complete, view of the market (self-insured data was prohibited from individual state collection due, in part, to a lack of a consistent cross-state standard for its collection). State APCD agencies are also likely receiving data of subpar quality, as many of the payers that report to them are also required to report to other

states using different standards, creating reporting confusion and limiting cross-state data quality checks that a payer could perform. Payers confront significant and costly administrative burden in meeting each state's requirements—a burden that grows with each year and each new APCD state—but have little leverage or bandwidth to protest individual state regulatory requirements. Data users seeking claims/encounter data from multiple states confront challenges in harmonizing data across state APCDs, lessening demand and a potential source of needed revenue for state APCDs. The current state is a functional and workable, but sub-optimal outcome for states, payers, and data users.

Alternatively, should state APCD agencies harmonize their data collection specifications and practices, creating a common data standard and a single governance process to manage that standard, they may potentially benefit from: more complete data collection, if ERISA-preempted, self-insured data is allowed to be collected; higher quality data, as payers report to one standard, reducing reporting confusion, and states can implement common data quality checks; and additional revenue, as demand increases for data that is more easily integrated and analytically useful across states. In such a scenario, payers' reporting burden would be reduced significantly, reporting to one standard—likely with state specific codes within standard data fields—and would only need to participate in one data governance process to manage data specification changes across states. Data users would be able to cleanly integrate state APCD data, increasing demand and potential revenue for state APCD data. This “potential state” is a highly functional and efficient data exchange ecosystem that improves the comprehensiveness and quality of the data being exchanged, and improves the volume and utility of data put into practice.

However, state APCD agencies confront several barriers to moving from the “current state” to the “potential state.” The biggest incentive for states to pursue data standards alignment would be the promise of ERISA-preempted, self-insured data. The pathway to unlocking ERISA-preempted, self-insured data for analytic use would require states to collectively agree on what a data standard is and agree to adopt it. State APCD agencies are unlikely to adopt a common data standard—particularly given the spectrum of data collect specifications presently in place—without a guarantee that the ERISA-preempted, self-insured data would become available, a firm understanding of how a national standard and standard-governance process could be established that would still allow individual state coding needs to be reflected, and financial and technical assistance implementation support to make the changes in their data collection processes, which their individual budgets would not allow. The federal government, payers, and philanthropic organizations are all well-positioned to catalyze and financially support states in the pursuit of a common data standard and break the Prisoner's Dilemma in which all APCD stakeholders presently find themselves.

State APCD agencies are unlikely to adopt a common data standard—particularly given the spectrum of data collect specifications presently in place—without a guarantee that the ERISA-preempted, self-insured data would become available.



## Potential Solution Strategies

Potential strategies to address state APCD data standardization issues, include:

**(1) Establish multi-stakeholder collaborative to develop a national APCD data standard:** The APCD SAG, as established, supported by an SDO, and charged with realizing [Opportunity #2.1](#) by “advance[ing] a uniform national APCD data standard to support self-insured data collection by states,” should ensure that the “national APCD data standard” that it develops will not only support the uniform collection of self-insured data, but also will support state APCD data collection across lines-of-business. While developing data standards for all lines-of-business simultaneously will require the engagement of additional stakeholders (e.g., Medicaid agencies, ACA marketplaces, state insurance commissioners<sup>332</sup>) and a higher level-of-effort on behalf of participants, it would also result in substantial efficiencies and would reduce the risk of the self-insured APCD data standard—which will need to be approved by the DOL—requiring immediate and avoidable changes due to unforeseen data relationships to other elements of the APCD files with which they would need to be integrated.<sup>333</sup> The national APCD data standard should be advanced on the same schedule proposed for the self-insured data standard (one year), submitted to the governance body of any National HDO (if established) for review and approval, and similarly be released for public comment. The standard should be governed by the same process established to govern self-insured APCD data standard changes.

The national APCD standards development process would likely need to be started by federal leaders, providing assurance that it would result in the ability to collect ERISA-preempted, self-insured data, but may otherwise be funded or supported by philanthropic organizations and payers.

**(2) Establish a national APCD data standards governance entity:** As discussed in the solution strategies for [Opportunity #2.1](#), a process for maintaining a national APCD data standard will be essential, as will the establishment of a credible governance entity to ensure the process is followed and to make final decisions on proposed standard modifications. For a self-insured data standard, the sole “governance entity” could be the DOL, in its role overseeing ERISA; however, oversight of the standards for the other lines-of-business, and how these data comprise cohesive files that are delivered to state APCDs, a broader governance entity will likely be required.

This paper proposes the establishment of a shared federal-state-consumer privacy governance structure to oversee the operations of a national HDO, including approving changes to the standards by which it collects data from payers for states and other users (see [Section VI](#)). This governance body would be required to meaningfully engage payers and TPAs in standards setting, and would be supported by an SDO in performing its duties.

However, in advance of the establishment of a national HDO governance body—and to inform possible state implementation asks (see next strategy)—NAHDO and the APCD Council may proactively work with state APCD agencies to identify the state-by-state changes required to comply with a standard similar to that of the CDL. NAHDO and the APCD Council may also work with states to proactively develop possible implementation strategies, modeling how new data standards may be operationalized without disrupting present state APCD dataflows and reporting (e.g., parallel processing, centralized collection). This work

may be supported by a federal grant from AHRQ (which has a significant history of supporting state data standardization for research purposes) and by philanthropic organizations, and would provide an important foundation on which broader system change could occur to minimal disruption.

**(3) Provide state APCD agencies with data standardization implementation support.** Congress should appropriate CAA state APCD capacity building funding, potentially increasing funding to \$4 million per state over three years (see Section IV.4), with the prerequisite that funding eligibility is dependent on participation in national APCD data harmonization. The DOL may further incent compliance with the ability to collect self-insured data (see [Opportunity #2.1](#)).

**(4) Support cross-state knowledge sharing to support payer data harmonization:** As previously discussed, even with a national APCD data standard, payer-specific transaction and data management practices—that are not otherwise standardized—will likely result in the continued need for state harmonization of the payer data it receives (e.g., versioning). NAHDO and the APCD Council may solicit and share common state practices for addressing payer data variation to support state data curation. For example, NAHDO/APCD Council could develop a payer versioning index, wherein states may record information on payer versioning practices and harmonization strategies. NAHDO may seek funding to support these important data harmonization activities from state members, AHRQ, or philanthropic organizations.

### #3.2: Harmonize State APCD Data Curation Practices

Each state APCD maintains its own edit checks for payer data submissions. Developing and maintaining the editing process is resource-intensive for state APCDs and their data collection vendors. The process comprises, as previously discussed in Section III.A:

- Establishing data quality requirements and thresholds by APCD data file and field;
- Reviewing submitted data in accordance with these requirements and thresholds;
- Reporting failed files and fields back to payers with actionable information to facilitate resolution;
- Providing ad hoc support to address concerns or establishing payer-specific exceptions;
- Reviewing re-submitted data to ensure compliance; and
- Documenting and communicating data limitations to internal and external data users.

For payers, the process is also arduous. Payers may submit the same APCD file and fields to one APCD and have it accepted but have it rejected in another. Variation in how state APCDs test and accept-or-reject data creates another layer of submission and compliance complexity for data submitters—and requires their teams' manual effort to understand why files were rejected, how to resolve issues, and/or engaging the state in discussions about why data is accurate or unable to be provided in the desired format (or level of completeness).<sup>334</sup>

For data users, state-by-state quality assurance variation can result in uncertainty over whether common APCD data files and fields—once harmonized across states—represent data that has been similarly vetted.

#### Potential Solution Strategies

Potential strategies to address the administrative burden created by cross-state APCD data curation practices, include:

##### (1) Developing common state minimum editing requirements and facilitating broader editing

**harmonization:** Similar to facilitating state data standardization, NAHDO and the APCD Council, with funding from a philanthropic organization, can inventory current state APCD file and field edits and thresholds, and facilitate cross-state consensus on opportunities for file- and field-level data quality check harmonization.<sup>335</sup> Should a national HDO governance entity be established and held responsible for overseeing a national APCD data standard, it may also be charged with setting minimum national data quality thresholds to reduce variation in payers' state-by-state submission experiences.<sup>336</sup>

### #3.3: Promote and Reinforce State APCD Data Privacy and Security Protections

As discussed extensively in Section III.B, states balance APCD data privacy and data utility in: the data they choose to collect; how they manage the data; and who they allow to access the data internally and externally, and for what purpose. State APCD agency leaders interviewed for this paper—and witnessed in practice by its author—universally view data privacy and security as their most important responsibility and greatest institutional risk: an observation not often apparent by viewing state APCD websites or communication material. Most state APCDs do not profile their data privacy and security practices and protections as “homepage” issues; if spoken to, they are usually addressed on pages deep within their websites that often require external search engines to efficiently find. Once found, state APCD data privacy and security communications are not unusually drafted in a manner that concerned residents (or the policymakers and press that represent them) can easily understand.

State APCD agencies’ lack of up-front, accessible information about the data privacy and security practices they employ can result in misperceptions about the extensive and rigorous practices they have in place, as well as the federal and state laws that govern how individuals’ data in an APCD may or may not be used and by whom. In a national environment suspect of public institutions and how their health data is being used, state APCD agencies will likely face increased bipartisan questioning and scrutiny about how APCD data are protected and used, which their leaders should be prepared to answer quickly and conclusively.

#### Potential Solution Strategies

Potential strategies to address potential misperceptions of state APCD data privacy and security, while further bolstering those protections, may include:

**(1) Developing minimum state APCD health data privacy and security standards:** An established national HDO may set minimum data privacy standards for participating states (see Section VI), creating an undisputed floor for how state and national APCD data may be collected, viewed, used, and released, likely mitigating many stakeholders’ concerns. However, a national HDO is not required to achieve this goal. State APCD agencies today, potentially facilitated by NAHDO and the APCD, can inventory current state-by-state APCD data privacy and security protocols and practices, and develop minimum standards that all could abide by—and communicate compliance with. State APCD agencies may wish to communicate its compliance through a common certification process, administered by a contracted third party, that allows them to publicly cite the quality of their data stewardship.

**(2) Supporting data privacy and security transparency:** State APCD agencies should universally post a link to information about “Data Privacy and Security” practices on their homepages. State APCD Data Privacy and Security pages should speak to, in broadly accessible language:

- The federal and state laws in place that protect individuals’ health information; and
- Additional practices and protocols the Agency has instituted to further protect access or unintended disclosures.

Website communications should also speak to, based on the aforementioned protections:

- What entities and individuals are able access APCD data, to what extent, for what purposes, for what duration, for what cost, and after going through what vetting;
- How APCD data is protected whether “at rest,” “in motion,” or during approved analyses to prevent re-identification;
- What limits are in place for access and use of data that may not be considered PHI, but which may be used for unapproved investigations or to discriminate against certain populations; and
- How is the Agency and its data users held accountable for maintaining these protections.

California, for example, publicly shares that its APCD (“HPD”) data is available only through a secure data enclave, a “centralized service to remotely access secure data... a secure environment [that] protects.... data in accordance with state and federal security and privacy laws... [which ensures] data products created on it can only be downloaded” with agency permission.<sup>337</sup> Colorado’s CIVHC provides helpful graphics that illustrate how encryption works to further reduce concerns from a lay audience.<sup>338</sup>

State APCD agencies may wish to partner with local philanthropic organizations to support the development of data privacy and security communications, which may comprise documentation and videos.

### #3.4: Harmonize State APCD Data Access Requirements

State APCD data availability and access requirements vary across states, as discussed extensively in Section III.A, diluting the value proposition for data users interested in conducting cross-state analyses, and often driving them to expensive and more limited private health data alternatives (see Section II.A). State APCD agencies have no application commonality or review determination reciprocity. Data users seeking data from multiple state APCDs—including researchers, purchasers, consumer advocates and even federal and state regulators—can expect to:

- Complete data request applications that request different information;
- Pay multiple and highly variable data acquisition fees;
- Manage different data application review processes;
- Comply with different DUAs and data security requirements; and
- Attest to different data destruction processes.

Some states may allow for direct APCD data delivery and download into local environments, while others may require that APCD data remain in their secure and isolated “data enclaves,” which may limited users’ ability to link acquired state APCD data with other data sets, including other, acquired APCD data.

Administrative burden and time delays to support multiple state APCD applications can be significant, and compounded by the—previously discussed—subsequent investments data users must make to harmonize the APCD data they receive from each state to support cross-state analytics.

#### Potential Solution Strategies

Potential strategies to support the harmonization of state APCD data access requirements include:

**(1) Develop a common data application:** State APCD agencies interested in establishing a common application, potentially coordinated by NAHDO or the APCD Council, could inventory current state APCD data application criteria and identify where harmonization is possible. A common APCD data request application can set a baseline of information needed for all participating APCD states; the application would likely still need to be supplemented by limited but additional state-by-state requests, so participating states can satisfy unique and local regulatory requirements.<sup>339</sup>

The development of a common APCD data request application would also require a common application review process and would benefit from a common application portal. A common application submission process would require a common submission starting-point and response-end point, but the review process could vary based on participating APCD state preferences. The review process could be centralized, with the implicated states actively engaging to determine approvals (which may require modifications to current local practices), or decentralized, with the implicated states each receiving the application for review, as if submitted locally. The application submission

The development of a common APCD data request application would also require a common application review process and would benefit from a common application portal.

and review process would benefit from a common application portal to make the user experience as simple as possible, with backend functionality that facilitates communication between states implicated in the reviews and the requestor.

The development of a common application can be piloted by willing state APCD agencies today without the need significant external support, though the process—and the development of a common portal—would benefit from philanthropic-supported project management.

**(2) Incentivize application uniformity:** Congress or federal administering agencies could require states wishing to access CAA APCD capacity building funds, if appropriated, to participate in data standardization and/or data application harmonization efforts. The federal government could provide a grant to NAHDO to establish a common application portal on behalf of its APCD member states.

### #3.5: Enhance State APCD Resources to Support Analytics

State APCD agencies can enhance the usefulness of the data they grant access to by improving user documentation and fostering engaged user communities to provide peer support with data use.

New state APCD data users are often granted access to APCD data with minimal documentation on how the data can be effectively used beyond publicly posted data submission/user manuals and links to prior user group webinars (if available). New state APCD users would benefit from analytic user guides that not only describe what data the APCD files they receive comprise, but instructions and guidance on how the APCD data they receive may be effectively integrated and used for analytic purposes.

New state APCD data users often also feel isolated in their analytics, with few connections to individuals outside of the APCD agency with whom they can discuss and troubleshoot identified data anomalies or analytic questions. New state APCD users would benefit from being connected to states' growing APCD user communities.

Addressing these gaps could foster more engaged user communities, improve the quality of external APCD analytics and products, and result in higher demand for state APCD data.

#### Potential Solution Strategies

Potential strategies to strengthen state APCD data analytic utility include:

**(1) Develop detailed state APCD analytic user guides:** NAHDO and the APCD Council, on behalf of states, should review state APCD and private sector analytic user guides to identify best practices. Findings can be presented on an open APCD Council webinar. The webinar could include presentations from "leading" APCD states (in this area), and include information on how such investments can improve the user experience and demand. State APCD agencies should invest in developing these materials with local user input.

**(2) Foster state APCD analytic learning communities:** State APCD agencies can foster connected, engaged, and active APCD user communities through:

- Automatically enrolling data recipients in an APCD Data User listserv (opt-out option available), with information on how to access resources and user forums;
- Establishing a wiki-page for users to access internal/external user generated notes on APCD file, field, and/or payer submission anomalies and ask questions to avoid cycles of issue "rediscovery," fostering data transparency and democratization; and
- Creating a repository of open source APCD analytic code, where internal users can post code used to produce all public reporting and external users can post code used to conduct their analyses, for future users to benefit from.

Local philanthropic organizations may be engaged to provide capacity-building funds to support the development of these resources. State APCD agencies would likely need to dedicate ongoing staff resources thereafter to manage the user community and established forums.



### #3.6: Strengthen State APCD Analytic Methodology Alignment

State APCD agencies frequently pursue common analytic use cases independently, which can forgo the opportunity to collaborate on analytic methodology development. Co-development of analytic methodologies, when possible,<sup>340</sup> can:

- Reduce the burden and expense of methodology development on a single state APCD agency;
- Strengthen the methodology by bringing additional perspectives and expertise to bear;
- Allow for cross-state benchmarking, when the methodology is consistently applied; and
- Support the development of a stronger cross-state or national narrative on findings.

For example, several states have recently invested in primary care spending analyses—investigations of how much of our health care spending is invested in preventive services like primary care—with the goal of using that information to spur broader health system change. Each state developed a unique methodology, which it then applied to its APCD data. One state found that approximately 9.4% of the state’s non-pharmacy medical spending was for “primary care” for its investigated population and time period;<sup>341</sup> while another found that “primary care” spending for its population ranged from 11% to 14%.<sup>342</sup> While each report generated baselines that could be valuable to track primary care spending patterns over time in their respective states, the lack of methodological alignment prevented these states from benchmarking against one another as they pursued local policy actions, advancing a common analytic definition of “primary care” that could be used by other states—or the opportunity to more simply communicate broader health system reform needs (a focus area of the [Milbank Memorial Fund](#)).<sup>343</sup>

#### Potential Solution Strategies

Potential strategies to support cross-state APCD analytic alignment include:

**(1) Develop common methodology templates:** NAHDO and the APCD Council could work with APCD states to develop a methodology “template” that provides users a quick understanding of an investigation’s data parameters, including, but not limited to, inclusion/exclusion criteria for: time periods; populations; payers and line-of-business; services or end dates; service categories (with definitions); provider categories (with definitions); clinical conditions/diagnoses (with definitions); payment fields; other data; and calculations made. In alignment with solution strategies proposed for [Opportunity #3.5](#), states can also publicly post the code they used in creating the analysis for other researcher and state use.

**(2) Establish national APCD analytic learning communities:** NAHDO and the APCD Council, potentially with funding support from federal agencies like AHRQ, may support the development of cross-state APCD learning communities around particular topics of national interest (e.g., primary care, opioid prescription monitoring by prescribing physician, provider price variation analyses).<sup>344</sup> Learning communities can facilitate the development of common methodologies across states and other data users for analytic approaches and serve as operational knowledge-sharing opportunities across states. State products and collective lessons learned could be documented and published for ongoing reference.

## Opportunity #4: Address State APCD Agencies Financial and Workforce Needs

State APCD agencies—and state HDOs more broadly—are not traditional state programs that provide consumer services or fulfill specific regulatory functions. State HDOs are investments in market transparency and evidence-based decision-making, made with the goal of fostering more efficient and effective health care systems. State HDOs support health data use across state government departments and programs and among private actors, leveraging multiple data assets to derive new, actionable, nonpartisan intelligence about the performance of our systems of health and their successes and deficiencies. Their value is not easily quantifiable.

Given state HDOs' lack of direct public constituencies and the impact their data can have on powerful market actors, state HDOs can be vulnerable to political pressures, shifting policy priorities, and economic cycles. State HDOs' budget requests for needed infrastructure potentially challenged and may be constrained by state regulations as they work to attract and retain the technical workforce they require.

Resolving issues is critical to supporting transparent and accountable state health care ecosystems.

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### #4.1: Establish Adequate, Sustainable, and Protected Funding Support for State APCD Agencies

State APCD agencies—and the state HDOs they typically serve as—require adequate and sustained funding that is insulated from political pressures, changing policy priorities, and economic fluctuations to effectively realize the value of their data for the public.

#### Budget Adequacy

State APCD budgets are small relative to other state data and analytic investments in Medicaid and public health and similar private sector stewards of health care claims data, currently ranging from \$800,000 to \$8 million per year, averaging approximately \$3.5 million for a mid-sized state with modest analytic capacity (see Section III.D).<sup>345,346</sup> While information is not readily available for private claims database expenditures, expenditure information is available for public-serving non-profits. According to IRS Form 990 submissions from 2020, HCCI spent \$6.8 million on its operations, including its national claims data collection and analytic activities;<sup>347</sup> FAIR Health spent \$26.4 million.<sup>348</sup> IBM's for-profit Watson Health business, which included the MarketScan family of data sets and products (including national claims data), was generating roughly \$1 billion in annual revenue before it was sold to Merative in 2022.<sup>349</sup>

However, even with limited budgets, state APCD agencies must still acquire—directly or through a vendor (see Section III.C)—the same technology, analytic infrastructure and staff as private sector entities to support their health data and analytic objectives, including:

- Secure and efficient platforms and systems to intake, curate, manage, integrate, and support the analysis of substantial data sets from dozens of payers in alignment with specific business and technical rules;
- Secure servers to house production and analytic data with rigorous access controls;
- Critical analytic fields to support data linking or use cases, such as master member and provider identifiers and episode-based groupers (e.g., procedure, encounter, condition);
- Analytic, statistical and data visualization applications (e.g., SAS, STATA, R, Tableau);
- Customer relationship management (CRM) tools to manage information from external data requests to payer edit check thresholds; and
- A workforce—from data privacy attorneys to analysts—to support the development of new use cases for data users (see [Opportunity #4.2](#)).

While state APCD agencies may be able to attract mission-oriented staff and even groupers/technologies at a discount from market rates, state APCD budgets rarely have room to invest in anticipatory or proof-of-concept use cases that demonstrate greater market value and utility, which are critical for building a market for this public data. State HDOs require greater funding than they typically receive to demonstrate the full utility of the data they steward.

### **Budget Sustainability and Protection**

State APCD agencies are heavily dependent on annual state General Fund allocations (see Section III.D), which may shift for reasons outside the agency’s control such as shifting policy priorities, political pressures, and economic conditions. While state APCD agencies are not alone among state offices in their General Fund dependency, as statistical agencies without direct public constituencies, their natural protections against budget cuts are generally weaker. Legislators may view cuts in state APCD agencies’ budgets as having little direct, short-term impact on the day-to-day lives of constituents with minimal potential for political blowback: necessary concerns when making tough budgetary decisions in tight fiscal environments. State APCD agencies/HDOs that do not proactively work to build public constituencies, strong relationships with their legislators and appropriations, and deep linkages to essential work that their peer agencies and offices perform, may find themselves financially vulnerable.

For example, in 2012, Massachusetts established CHIA, its quasi-independent HDO and APCD-steward, to “improve health care quality and contain health care costs through transparency, efficiency and innovation.”<sup>350</sup> CHIA would depend on the state legislature to approve its budget—an assessment on the state’s payers and providers—to support its activities. CHIA pursued its mission rigorously, using its state health care cost growth benchmarking program<sup>351</sup> and APCD to identify, for the first time, payers, providers, and services that were driving state healthcare spending higher. In its first reports, CHIA called out the state’s largest provider organization as a high-cost and high-cost-growth organization.<sup>352</sup> In May 2016, late in the state’s largely settled SFY17 budget process, a negotiation between the large provider organization, a union, and the legislature resulted in legislative leaders diverting \$45 million from CHIA’s budget over

the succeeding five years to other priorities: a redistribution that would have structurally incapacitated the agency.<sup>353</sup> No rationale was offered for why the funds were diverted from CHIA. While CHIA's budget was ultimately restored through the years that followed thanks to strong consumer and peer state agency advocacy, the experience highlights the real budgetary vulnerability all state HDOs confront—and the influence external and well-resourced health care actors can wield over that process, especially when they feel threatened or blindsided by the HDO's reporting.

Tennessee's APCD faced similar challenges in 2016 with a less favorable outcome. The TN APCD was established in 2009 within the Tennessee Department of Commerce and Insurance (TDCI) to:

- Improve the accessibility and affordability of patient health care and health care coverage;
- Identify health and health care needs and inform health and health care policy; and
- Evaluate the effectiveness of intervention programs on improving patient outcomes.<sup>354</sup>

The TN APCD received state and federal funds to support its implementation, including part of a nearly \$4 million CMS/CCIIO Cycle II Grant in 2011. However, in 2016, amid changing political winds, new TDCI leaders publicly requested an opinion from the state's Attorney General about whether the state was required to continue to sustain its APCD in light of the Supreme Court's *Gobeille* decision. The Attorney General's office responded that given it was "not 'fairly clear of doubt' that the General Assembly would have [approved of an APCD] without being able to have health claims data reporting requirements imposed upon ERISA-governed group health plans," TDCI had the authority to cease its operations should it wish to, which it did.<sup>355</sup>

The Massachusetts and Tennessee experiences reinforce the risks state HDOs have in their structural dependency on state budgets as statistical agencies without direct public constituencies and with data that can challenge powerful interests.

### Potential Solution Strategies

Potential strategies to support state APCD budget adequacy, sustainability, and insulation include:

**(1) Provide federal financial support for sustaining state APCDs:** As discussed more comprehensively in [Opportunity #1, Solution Strategy #1](#), CMS, in coordination with the OMB, could help to address this need by providing a permanent source of federal financial support for establishing and sustaining state HDOs that steward APCDs by more fully matching state contributions. Access to federal matching funds would mitigate agency reliance on state general fund dollars and provide incentive for state appropriators to avoid cutting leveraged state dollars (i.e., cutting one dollar of state spending cuts at least a dollar in state revenue).

**(2) Redirect state APCD operating expenses from data collection to analytics:** As discussed more comprehensively in [Opportunity #1, Solution Strategy #2](#), to the extent local regulations permit, state APCD agencies may outsource data collection to another state APCD agency or a health data utility—creating a regional data collection operating model—to benefit from economies of scale and reduced costs; savings may be reallocated to support agency analytics that produce value to key stakeholders.

**(3) Institutionalize budget protections and accountability for state HDO funding:** State leaders can protect their HDOs, while maintaining program accountability, by institutionalizing new financial models, requirements for budget transparency, and governance structures for the organization.

(A) Instituting Protective Financial Models: States can institute alternative funding models for HDOs that remove general fund dependency, include checks-and-balances on budget requests, and open new sources of funding for major infrastructure investments. Funding model changes can include:

- Transitioning state HDO budget sourcing from state general funds to an assessment on health plans and providers, similar to Massachusetts' and Maine's present HDO model (see Section III.D), and the model maintained by many state insurance departments. States may require that an independent board and/or the legislature approve the level of the assessment.<sup>356</sup>
- Requiring budget requests be approved by an independent board that includes representatives from state departments, payers, and providers, adding external validation and pressure to the request.
- Depositing HDO funding in a dedicated HDO account for independent budgeting.
- Allowing for HDO long-term information technology (IT) investments to be included in the annual state capital budgeting process, to the extent IT investments are permitted.<sup>357</sup>

(B) Budget Transparency: States can require their HDOs to publicly report on their annual activities, budgets, and budget requests at a public hearing or before the public in another setting. Public hearings/presentations would allow HDOs to highlight the value they bring to the state health care system through quantifiable information (where possible) and public testimony; it would also allow HDOs to hear from the public on future priorities. State legislatures/governors may be required to provide written justification for cuts to an HDO's requested budget.

(C) Independent Governance Structures: States can require that HDOs maintain formal boards or steering committees that must be publicly consulted on and approve annual budget requests prior to submission to the legislature for approval. Board/steering committee input should be documented and shared with the legislative budget request.

Philanthropic organizations can play an instrumental role in further developing these financial and governance models to insulate state HDOs nationally, and locally, funding technical assistance to support their design (e.g., model bill drafting) and implementation.

**(4) Emphasize APCD-Data Derived Value:** State HDOs stewarding APCDs should develop strategic communication plans that engage data users in presenting the value and impact of APCD data. This can include:

- Requiring external data recipients to provide "closing reports" that document the value and impact of the data on consumers and market performance.
- Requesting state agencies provide annual letters in support of budget requests, communicating how they use the data and its impact on program functioning.
- Soliciting written feedback from key stakeholders/data users annually (e.g., consumer groups, good governance organizations) speaking to the data's utility and in support of continued funding.

- Privately reminding state legislators and Administration staff to voice support for the HDO's budget in the annual cycle. (State HDO leadership should be regularly engaging with Administrative and legislative staff: responding to information requests; commenting on bills to shape health data requests; and briefing on the breadth of activities the HDO undertakes.)

State HDOs should consolidate stakeholder feedback into their annual reporting (see previous Solution Strategy) as well as communications tailored to key constituencies (e.g., legislator staff, consumer advocates, data submitters), emphasizing use cases the agency supported that have bipartisan resonance (e.g., health care cost growth, surprise billing issue elevation, pharmacy cost transparency, opioid response support). NAHDO and the APCD Council, potentially in partnership with the National Conference of State Legislatures (NCSL), would be well-positioned to develop and share best practices targeted to legislators.

**(5) Serve the Data Submitters:** State HDOs stewarding APCDs should establish a permanent workstream focused on serving data submitters (payers) and providers, which few presently do.<sup>358</sup> As MPCDs have demonstrated, serving data submitters can be a self-sustaining business model, addressing a need for cross-payer and consolidated provider reporting (see Section II.A). Working with data submitters to develop products that can be useful for their business needs can:

- Lessen payer opposition to the state HDO's activities and any assessment that may be instituted ([Opportunity #4.1, Solution Strategy #3](#));
- Foster productive staff-level communications and relationships between the HDO and the payers; and
- Improve data quality, introducing new incentives for both the HDO and the payers to assess data validity to support market reporting.

To advance this strategy, NAHDO or the APCD Council could host a webinar series on how state APCDs and MPCDs have been used to support payer and provider reporting needs. The series could pair state HDO and payer/provider representatives. State HDOs can then work with their payer and provider communities to prioritize reporting needs and develop reasonable workplans to meet those needs.

**(6) Strengthen Services for Peer State Agencies:** State HDOs stewarding APCDs should regularly work to identify the health system data needs of peer state agencies (e.g., Medicaid, insurance, marketplaces) and develop structural data access and reporting solutions to meet those needs. State HDOs/APCD agencies should document product delivery arrangements in Interagency Service Agreements that either prescribe budget to the activity (i.e., ongoing budget transfers between the customer agency and the state HDO) or note the value of the in-kind support provided. Such documentation may be used by the state HDO to justify its annual budget requests.

## #4.2: Develop Staffing Strategies to Attract and Retain a Mission-Oriented Workforce

State APCD agencies require legal, business, technical and analytical staff who are familiar with health care administrative data, supportive HIT needs, and health data related issues (e.g., privacy requirements), and are capable of participating in the exhaustive process of translating raw payer claims data into analytic-ready datasets and reporting to support a spectrum of stakeholder needs. The demand for these jobs, however, is not limited to the public sector:

Growth in big data and its potential impact on the healthcare industry have driven the need for more data scientists. In healthcare, big data can be used to improve care quality, increase efficiency, lower costs and drive innovation...Healthcare organizations are investing in data scientist positions, with vendors and health systems seeking the most applicants...<sup>359</sup>

Growing demand has led “healthcare providers and payers [to compete] furiously with health IT vendors to secure experienced data scientists and machine learning experts in a highly competitive job market” to fill their persistent health data and analytics workforce gaps.<sup>360</sup> Demand for legal experts in data privacy and cybersecurity is no different.<sup>361</sup>

Intense private sector competition for health data talent can place public sector enterprises, like state HDOs at a disadvantage, often unable to match compensation offers—a gap that is potentially set to grow.<sup>362</sup> A recent analysis from the Pew Charitable Trusts found that “nationally, pay increases for state and local government employees haven’t kept pace with those of private workers, who generally have enjoyed much stronger gains as the economy recovers...[An] analysis of Labor Department data shows that year-over-year growth rate for hourly private sector salary and wages in each of the past four quarters has exceeded that for state and local governments by the largest margin on record. To make matters worse, public employee wages aren’t keeping pace with high inflation.”<sup>363</sup>

Intense private sector competition for health data talent can place public sector enterprises, like state HDOs at a disadvantage, often unable to match compensation offers—a gap that is potentially set to grow.

State HDOs often must press the limits of their state salary bands to recruit and retain health data talent—or rely on vendors to fill institutional state roles (see Section III.C)—though still report high staff turn-over, particularly for entry-to-mid-level programmers and analysts.

### Potential Solution Strategies

Potential strategies to address state HDO staffing concerns include:

**(1) Strategically assess state HDO structure:** State HDOs will not be able to compete with the private sector for talent on compensation alone (see next strategy). However, state HDOs may have varying levels of flexibility in how well they can compete on compensation depending on whether they are required to comply with state government hiring practices and limitations.

HDOs that are embedded within state government, whether as an independent office or within a larger agency, must abide by state hiring practices, rules, and salary bands (with flexibility increasing outside union-based arrangements). HDOs that are located outside of state government, whether at quasi-public entities, at

non-profits or within academic institutions, have greater hiring and compensation flexibility, but potentially at the expense of benefits—and may experience program and operational challenges that those HDOs located within state government may not.

When considering the structure of their HDOs, state leaders should strategically assess whether the HDO should be located inside or outside of government—and the full value and costs such positioning presents to the organization. If locating the state HDO within a state department, state leaders may consider whether new salary structures, bands, or allowances can be created to allow these organizations to better compete for talent.

State HDO leaders located within state government should become highly educated about the state hiring structure, salary bands, and requirements for meeting classification levels. They should advocate for adding new bands for their staff and aggressively reclassify existing positions to better represent their technical nature, which can often open access to existing and higher IT salary bands.

**(2) Develop strategies to attract and retain a top-flight state HDO workforce:** While many state HDOs that steward APCDs—like state government departments more broadly—may not be able to compete for top-flight talent by compensation alone, they can compete by building upon other comparative advantages. State government agencies are uniquely equipped to create purposeful, balanced, and personally rewarding organizational cultures that can attract and retain a capable, mission-oriented workforce.<sup>364</sup> State HDOs should foster environments that:

- Offer flexibility in where and when employees work (while maintaining expectations of regular in-person connections to support team building, onboarding, and culture development);
- Reward entrepreneurialism, critical thinking, and creative problem-solving, with leadership that is unafraid of making structural changes to long-standing processes in favor of more effective alternatives;
- Offer staff cross-training and -project work, as well as meaningful opportunities for upskilling and professional development;
- Recognize accomplishments and increased capabilities with greater responsibility and title advancements;
- Direct personalized attention to accomplishments with individualized rewards; and
- Double-down on public work's public objectives, emphasizing the purpose, value, and impact of day-to-day work on citizens.

Developing a state HDO brand that focuses on the public good aligns well with new generational priorities.<sup>365</sup>

The investments state HDO leaders make in attracting and retaining high-quality, motivated staff have few equals with return-on-investment. State HDOs should have strategic, structured, and actionable workforce strategies that are regularly employed and annually assessed.



## V. The Imperative for National Change and Pathways Forward

State HDOs have demonstrated the value of APCDs to support market transparency and inform policy, program, and purchasing decisions. APCDs continue to proliferate across states with varied political leanings to support policymakers, regulators, and other data users as they work to address critical local health and health care system concerns. This section:

- Describes present and pressing national imperative to invest in and build from state APCD infrastructure to create national health system data capacity;
- Outlines guiding principles to guide the development of a new, national model for APCD data collection and use;
- Offers and rigorously assesses potential national APCD operating models; and
- Recommends a national APCD model for pursuit.

### A. The Imperative for Change: Building National Health Data Infrastructure

Health care spending in the United States now comprises one out of every five dollars of our national income, and is only expected to grow.<sup>366</sup> From health insurance premiums to out-of-pocket spending to expenditures on public health care programs, health care spending continue to rise unabated, crowding out other household and public spending priorities:

- **Premiums:** In 2022, health insurance premium costs reached \$22,463 for a family plan, with over a quarter of that paid for directly by employees (28%) and the remainder borne by employers (72%).<sup>367</sup> According to a survey by Willis Towers Watson, seven in ten employers are expecting “moderate to significant” increases in their health care costs in the next three years; only 20% of employers reported that they would increase funding for their plans without increasing employee contributions or reducing other employee benefits.<sup>368</sup>
- **Out-of-Pocket Spending:** To mitigate premium cost growth, employers and employees are opting for plans that carry higher deductibles, replacing premium costs with new direct-pay liabilities for health care services. In 2022, the average deductible for single coverage reached \$1,763; 15% of workers had a deductible that exceeded \$3,000—with that proportion doubling for workers at small firms.<sup>369,370</sup>

From health insurance premiums to out-of-pocket spending to expenditures on public health care programs, health care spending continue to rise unabated, crowding out other household and public spending priorities.

- **Cost of Taxpayer Programs:** State agencies project Medicaid spending will grow by 12.5% during SFY22, driven by COVID-19-related enrollment growth.<sup>371</sup> The Congressional Budget Office (CBO) projects Medicare spending will grow by 8.5% in 2022.<sup>372</sup> Publicly funded Medicare and Medicaid spending is estimated to total over \$1.66 trillion in 2021—37% of national health care spending.<sup>373</sup> Medicare and Medicaid comprise approximately 21% of total federal outlays (more than Social Security and nearly as much as Defense and Nondefense Discretionary spending), and is the second largest state general fund expenditure (the largest including federal revenues).<sup>374</sup>

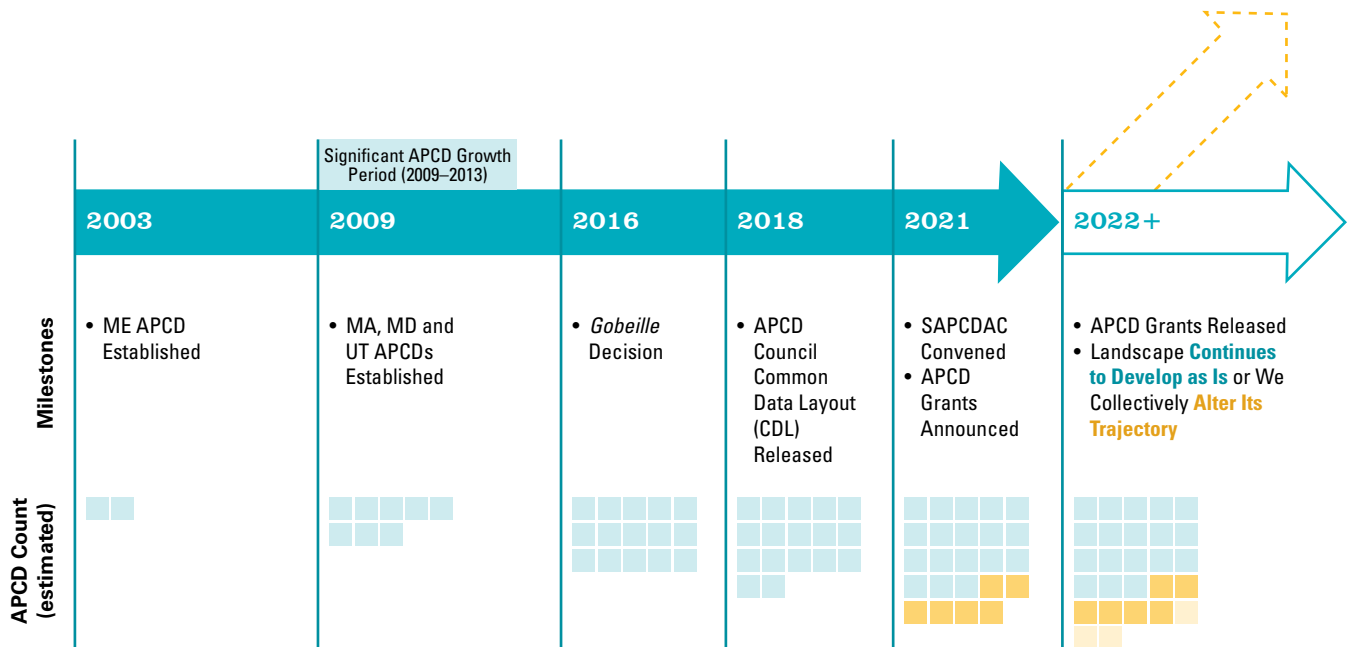
Total U.S. health care spending is estimated to have reached nearly \$4.3 trillion in 2021—or approximately \$13,000 per resident—and yet nearly half of American adults still have difficulty affording care and four-in-ten report delaying or forgoing care due to cost.<sup>375</sup> Racial and ethnic health disparities in our country are pervasive<sup>376</sup> and compounded by the divergent impact of COVID-19.<sup>377</sup> And despite America’s unparalleled level of health care spending, Americans’ life expectancies remain well-below those of peer countries.<sup>378</sup>

Addressing the shortcomings of America’s health care system requires an unobstructed view of how the system is operating, as it is operating, across populations, states, payers, and providers. It requires data that show how our health care system is making available, delivering, and paying for services, and how those services are impacting health outcomes. It requires system transparency and accountability. APCDs, clear-water basins of health care transactions, are protected state data resources that have the demonstrated capacity to support these objectives locally and—if properly invested in, harmonized, and built on—can address many of our nation’s health system information needs.

Addressing the shortcomings of America’s health care system requires an unobstructed view of how the system is operating, as it is operating, across populations, states, payers, and providers.

As more than six new states—including two of our largest, California and Texas—plan for APCD establishment by 2025, federal and state stakeholders have an opportunity to recast the state APCD operating and financial model to better support state, federal, and national health data needs.

Exhibit 16: State APCD History and Pathways Forward



Working together, state and federal leaders can build from existing state APCD infrastructure to establish a national health data system that:

- **Preserves state data ownership**, allowing state APCD agency staff, who know their markets best, to continue validating the data they receive, while maintaining the timeliest data access;
- **Harmonizes state APCD data collection**, lessening the reporting burden for payers and the analytic burden for multi-state data users, which **allows for full market data collection**;
- **Equips state HDOs with the stable financial resources** they need to support full market transparency and informed health care policy, program, and purchasing decision-making;
- **Provides states without APCDs with new information** about their health care systems;
- **Establishes national health data collection, data access, and analytic capacity**—accountable to consumer, state, and federal representatives—to support cross-state, regional, and national benchmarking and analytics with a single point of data access for federal and state policymakers, regulators, purchasers, researchers, consumer advocates, payers, and providers, with data revenue distributed back to states to support their local work; and
- **Raises standards for health data privacy and security** locally and nationally, ensuring patient information is better collected, managed, and used in compliance with a common national standard.

States cannot realize this change alone. Federal leadership—and partnership—is required to realize a national APCD model that invests in and builds from our state infrastructure to meet our collective goals. Driven by a national imperative to address issues of health care affordability, access, health, and health equity, equipped

with knowledge of our health system information needs and the ability of state APCDs to address those needs, and presented with a renewed opportunity to engage in bipartisan solutioning, congressional leaders have the opportunity to advance a health system transparency strategy that will empower federal and state policymakers and regulators, national purchasers, payers, providers, researchers, and consumers with the information they need to check our health care system's shortcomings.

## B. Guiding Principles for National APCD Operating Model Design

Throughout 2022, Manatt interviewed or received notes from over 40 federal, state and industry health data leaders to inform this paper and shape its proposals (see [Appendix](#)). The following principles were developed from these exchanges to guide the development of a national APCD operating model that would benefit state and federal policymakers and regulators, researchers, purchasers, consumer advocates, and other data users, as well as practical needs of data submitters (payers). The principles represent foundational priorities and guardrails—prerequisites for participants to willingly and productively participate and partner in implementing national APCD system change.

- 1. Health system data is a public good:** Stakeholders expressed strong consensus that administrative health data is a public good that should be used to support health system oversight and improvements that benefit all Americans. Presently, private interests have better access to health system data than public interests, creating public-private health information inequities, which have resulted in unbridled health care cost growth and severe gaps in health care access and equity. Advancing a health system data agenda for consumers was cited as a national imperative for most interviewees. Interviewees expected that any proposal to create a national APCD would face sharp resistance from stakeholders that have a financial interest in maintaining exclusive access to America's health system information.
- 2. States must maintain APCD data stewardship:** After years of significant investments, many state APCDs are now high-functioning data resources. While state APCD leaders acknowledged the limitations of the current APCD operating model, they were also hesitant to alter existing operations and jeopardize their ability to deliver on existing and valued data use cases for local stakeholders. State APCD leaders also shared skepticism that a federal or national data intermediary could satisfy their data timeliness needs.<sup>379</sup> Further,

Stakeholders expressed strong consensus that administrative health data is a public good that should be used to support health system oversight and improvements that benefit all Americans. Presently, private interests have better access to health system data than public interests, creating public-private health information inequities, which have resulted in unbridled health care cost growth and severe gaps in health care access and equity.

Interviewees expected that any proposal to create a national APCD would face sharp resistance from stakeholders that have a financial interest in maintaining exclusive access to America's health system information.

while Americans' trust in our public institutions remains at historically low levels, it remains stronger with state institutions than federal ones.<sup>380</sup> Any national APCD model should not jeopardize existing state operations or alter state HDO's roles as their states' primary APCD data collectors and owners.

3. **Federal help is required to address APCD limitations:** While states wish to preserve APCD data ownership, it is not without acknowledgment that federal support and action are needed to resolve state APCD data completeness issues. State APCD leaders are seeking federal assistance to allow for the standardized collection of data for: individuals covered by ERISA-preempted self-insured plans; SUD service claims from Part 2 providers; and individuals covered by or receiving services from federally administered health programs, such as Medicare, TRICARE, CHAMPVA, the FEHB Program, and IHS. Access to these data would allow state APCD agencies to support cross-market analyses and new use cases (e.g., provider market share assessments, health service inequity and disparity analyses).
4. **Data standardization requires data governance:** State APCD agency leaders expressed a willingness to make operational changes and implement a common data standard: with assurance that implementation would allow access to requested data; if funding for required system changes was made available; if the standard is developed and maintained to prioritize the inclusion of state-specific fields and codes; and if shared federal-state governance was established to maintain any resulting data standard.<sup>v</sup>
5. **Strong state health data use requires reliable and sustained funding:** States are responsible for overseeing increasingly complex and inter-connected health care markets, but often do not have the resources to build and sustain the necessary data and analytic capacity to meet the regulatory need. State HDOs—stewards of APCDs as well as other data assets, like hospital discharge data, hospital financial reporting, and cost growth benchmarking data—require sustained resourcing to support state health system information needs. Interviewees cited the need for a permanent source of federal funding to support state HDOs, absent federal action to address cross-state issues of affordability, access, health, and health equity.
6. **Data users and changemakers need better access to APCD data:** Potential users of state APCD data—particularly national health care purchasers, researchers, and consumer advocates, whose national health system improvement agendas require access to data from multiple state APCDs—must currently navigate complex and lengthy data application and access processes to acquire data. For APCDs to be effective tools of system change, their data need to be easier to acquire and integrate. An alternative national APCD model should advance a single-point solution for APCD access, while allowing for the collection and distribution of data fees back to APCD states.

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<sup>v</sup> Payer interviewees expressed an eagerness to “have a seat” in any national governance that may be established. Payers are equipped with the strongest understanding of how their data is collected and how it may be most effectively used. They expressed frustration that a payer representative was not included on the SAPCDAC. State APCD agency interviewees, conversely, indicated that payers should not be included in any formal, decision-making governance role, as they believed the appointee would consistently vote against data collection and use. However, all interviewees agreed that having consistent payer input in a nonbinding advisory role could be valuable and productive. Based on these assessments, this paper did not recommend including a payer representative on the national APCD governing body but did recommend requiring payer input on data submission changes (see Section VI).

7. **National health system transparency needed:** Federal leaders noted the paucity of health system data through the COVID-19 pandemic, and the limitations its absence had on federal-state response coordination. For federal policymakers and regulators to understand and effectively respond to regional and national population health and system performance concerns, they require access to national health system data. A national APCD is needed to provide insights into our cross-state health systems, population health, and public health issues, and to inform more targeted and responsive policy, program, and public health responses.

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8. **Payer reporting burden must be addressed:** Greater APCD data standardization can alleviate payer burden, while strengthening the case for national ERISA-preempted self-insured data collection. National payers will soon be required to submit APCD data to—and maintain data compliance with—more than half of states in compliance with different formatting, timing, and submission standards. The administrative burden payers confront for transforming and submitting data differently to each state APCD is real, costly, and growing. Most interviewees recognized the payer burden, and how addressing the burden could benefit payers, states, and cross-state data users long-term.

The administrative burden payers confront for transforming and submitting data differently to each state APCD is real, costly, and growing.

9. **National opportunity to strengthen APCD data protections:** State APCDs steward sensitive patient information that must be protected from unintended use. States that have established APCDs—and the HDOs that steward these resources—have implemented strong data privacy protections for APCD data and its use (see Section III.B). However, many interviewees identified the development of a national, state-based APCD system as an opportunity to standardize and elevate state APCD privacy protections, proactively addressing who can access what level of state and national APCD data for what purpose.

National APCD model recommendations have been designed to reflect these principles.

## C. Potential National APCD Operating Models

Stakeholders proposed and evaluated six potential national APCD operating models designed to improve health system data access and use locally and nationally:

**Model #1: Centralized model**, wherein a national entity would collect data and compile standardized membership and claims information from payers and TPAs across states and redistribute curated data back to participating states for analytic use. The model may be shaped as a:

- **(A) State Collaborative**, wherein APCD states establish a self-governing association, similar to the NAIC, to fulfill this role. The collaborative would not collect data or support analytics for non-participating states. The model would create cross-state data access and analytic capacity.
- **(B) Federal Entity**, wherein the federal government, directly or through a contracted National HDO, would fulfill this role. The federal entity would collect data and support analytics for all states. It would distribute data only to states that request it and comply with data access and use requirements. The model would create national data access and analytic capacity.

**Model #2: Decentralized model**, wherein payer membership and claims data would remain distributed and managed locally, but with new agreements, mechanisms and methods introduced to allow for greater data access and use. The model may be shaped as:

- **(A) Uniform State Analytics**, wherein the federal government would enter into a data-sharing agreements with APCD states. Participating states would execute federal data requests using their APCDs and share data extracts and/or analytic outputs back with the federal government for cross-state compilation and use. Data for states without APCDs would not be available. The model would allow for greater cross-state health system insights; it would not create new data access or analytic capacity outside of the federal government and APCD states.
- **(B) Uniform Payer-Based Data**, wherein the federal government would establish—for itself and APCD states—a common data-sharing agreement with payers and TPAs that would allow their APCD data to remain in payers'/TPAs' local environments, but would establish a protected pathway for permitted federal/state users to access and query that data, as needed. Data for all states would be available. The model would likely limit the types of analyses that may be conducted on compiled data.

**Model #3: Partnership model**, wherein states and the federal government would work together to improve collective data access and analytic capacity. The model may be shaped as a:

- **(A) Federal-State Data Trade**, wherein, similar to the model offered in the LHCC Act, the federal government and state APCD agencies would enter into a reciprocal data-sharing relationship. The federal government would collect self-insured and federally administered data from payers/TPAs nationally using a common data standard and distribute it to state APCD agencies in exchange for the data locally collected by those state APCDs. The model would allow for state APCD agencies to have access to complete market data; national data would be largely complete, with the exception data for states without APCDs and that choose not to participate.

- **(B) Federally Facilitated State Data Partnership**, wherein, similar to the Healthcare Cost & Utilization Project (HCUP) data collection model, states would maintain APCD data ownership and collection responsibilities, with responsibilities expanded to collect full market data using an approved national APCD standard, and report datasets to a new federally procured National HDO. For states without an APCD or that choose not to participate, the National HDO would collect APCD data directly from payers and TPAs operating in those states to complete a national sample. The model would create new national and state data access and analytic capacity.

Numerous variations of these options exist, though the key data exchanges represented in each are unique. Each model is discussed in detail in this section and then assessed against the following questions:

- Would the model expand APCD data collection to meet national analytic needs? (Section [IV.1](#))
- Would the model improve state APCD data completeness? (Section [IV.2](#))
- Would the model enhance cross-state data comparability and access? (Section [IV.3](#))
- Would the model support state APCD sustainability? (Section [IV.4](#))
- Does the model align with the Guiding Principles?<sup>381</sup> (Section [V.B](#))

For each of these questions, the model is assigned one of four ratings:

- **No:** the model would not address the identified gaps or needs in this area.
- **Limited:** the model would have a limited impact on the identified gaps or needs in this area.
- **Mostly:** the model would address many of the identified gaps or needs in this area.
- **Yes:** the model would address the identified gaps or needs in this area.

Model assessments and ratings are based on a core set of assumptions about model participants, their regulatory authorities, and other supportive actions that would be required to realize model design (see next section, “Model Assumptions”). **Proposed models must be paired with regulatory and financing solutions to realize an effective, comprehensive national health system data solution.**

### Additional Resources

The development of these models benefited from the thoughtful work that preceded it, including:

- Dr. Matthew Fiedler’s and Christen Linke Young’s paper in 2020, which recommended the creation of a national APCD (akin to the “Centralized, Federal Entity” model);<sup>382</sup> and
- A comparison of state APCD operating models undertaken by California as it weighed its own APCD pursuit.<sup>383</sup>



## Model Assumptions

Model designs are based on assumptions that include:

- The federal government—whether through existing agency regulatory authority or to-be-acquired congressional legislative authority—will have the ability to collect or allow for the collection of ERISA-preempted self-insured membership and claims data using a national data standard.
- Federal, state, and industry consensus on a national APCD data standard, transmission standards, and data governance model will be reached.
- Data privacy will be a paramount consideration in the implementation of any operating model, including setting data standards and data governance.
- States will receive implementation support to effectively implement the model, including financial support and technical assistance.
- Federal agencies responsible for implementation will be appropriately funded.
- New operating models will be implemented in partnership with states over time, running parallel to existing state APCD operations to avoid disruption.
- New operating models will be implemented by all responsible parties with appropriate oversight and public accountability.

## **Model #1: Centralized**

A centralized, national data collection model would fundamentally reshape the APCD landscape, moving data collection responsibility from states to a new national or federal entity, with the goal of generating operating efficiencies and unlocking access to federally regulated data. The entity would collect standardized membership and claims information from local and national payers and TPAs, and redistribute consolidated and normalized data back to states for local analytic use. The model may be advanced as a state collaborative, similar to that of the NAIC, or as a federal entity.

### **#1A: State Collaborative**

States with APCDs could establish a self-governing collaborative or association to collect data on their behalf from payers and TPAs operating in their states. A “State Collaborative” model for APCD data collection would be similar to and could potentially build from payer financial reporting currently maintained by the NAIC.<sup>384</sup> Data would be centrally collected using a common standard, reducing the reporting burden for payers, which would no longer need to customize submissions by state, and the collection and curation burden for individual APCD states. The collaborative would collect, curate, and normalize the payer data it receives before redistributing it back to states for analytic use. The federal government would allow the collaborative to collect ERISA-preempted self-insured data using the common data standard, filling a major gap in present state APCD data collection.

Establishing a multistate APCD collaborative may require participating states to pass legislation that would allow them to provide the collaborative local data collection and curation authority. Thereafter, state data collection interests would be represented through the collaborative’s governance process.

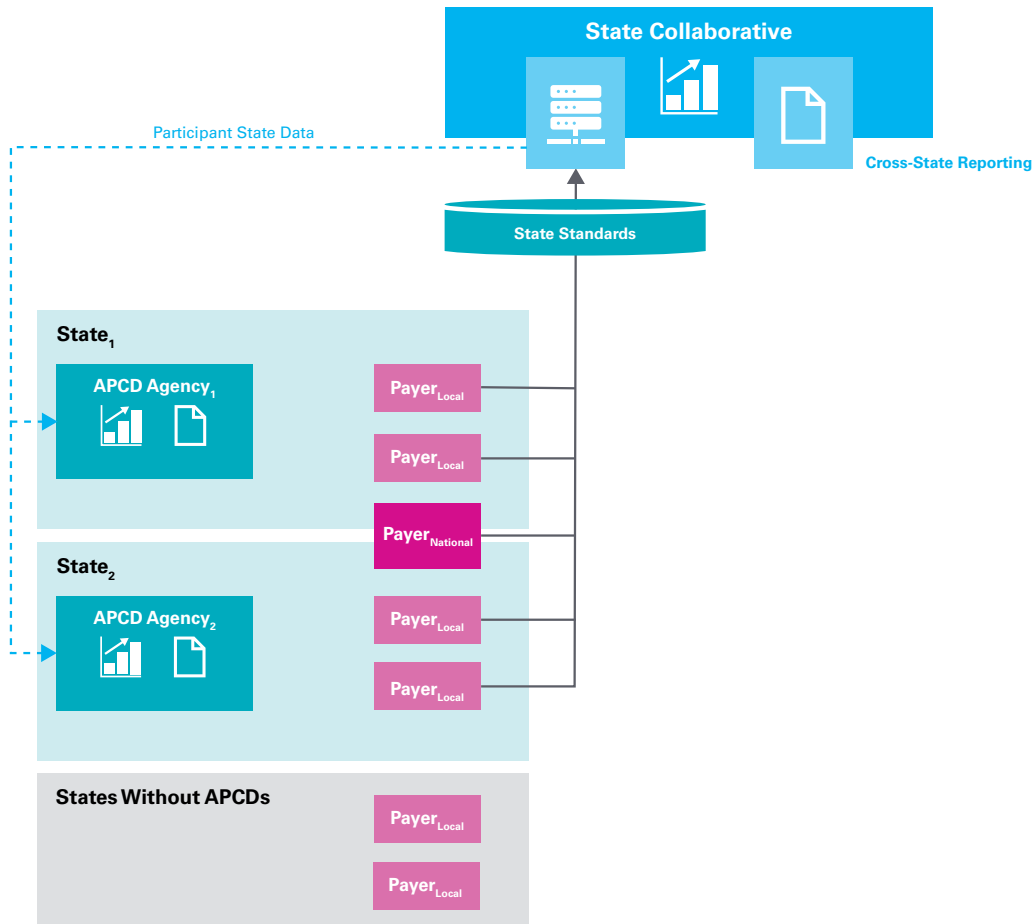
The collaborative’s governance body would be charged with representing state participant interests in data collection, curation, management, redistribution, and analytic activities; and overseeing the collaborative’s operations, from establishing and maintaining a common data standard to setting the rules, fees, and fee-distribution schedules for external data access.

The collaborative would be responsible for centrally:

- Developing, implementing, and maintaining a common data collection standard and editing process, including working with payers and TPAs to revise and resubmit submissions, as necessary;
- Creating data submission guides and releasing updates at a pre-determined interval;
- Collecting data from public and private payers and TPAs operating in participating states;
- Storing and managing data in a secure data environment and maintaining cybersecurity protections;
- Compiling, curating, and normalizing payer data for analytic use;
- Distributing analytic-ready data back to participating states;
- Managing a centralized, transparent, and consistent data request and application process;
- Setting a common fee schedule and distribution model for data acquisition;
- Ensuring data releases meet patient privacy protection standards; and
- Representing participant interests to the federal government and industry stakeholders.

The collaborative may also be directed by its governing body to analyze cross-state data to support federal, state, or public reporting needs.

Exhibit 17: Model 1A, Centralized, State Collaborative



Participating states would likely need to financially support the collaborative in its early years. Long-term, the collaborative model would allow participating states to divest themselves of data collection activities and expenditures and, through data sales, may support a self-sustaining and potentially revenue-generating model for participating states.

Once a collaborative is established:

- Participating states would receive regular deliveries of “analytic ready” data from the collaborative to support local use;
- States without APCDs may choose to invest in their own APCD, given the lower financial barrier to entry; and
- The reporting burden on payers and TPAs would decline (as individual state APCD reporting is sunset).

Data users would be able to request data from the collaborative through a single application and application process, reducing delays to cross-state data access.

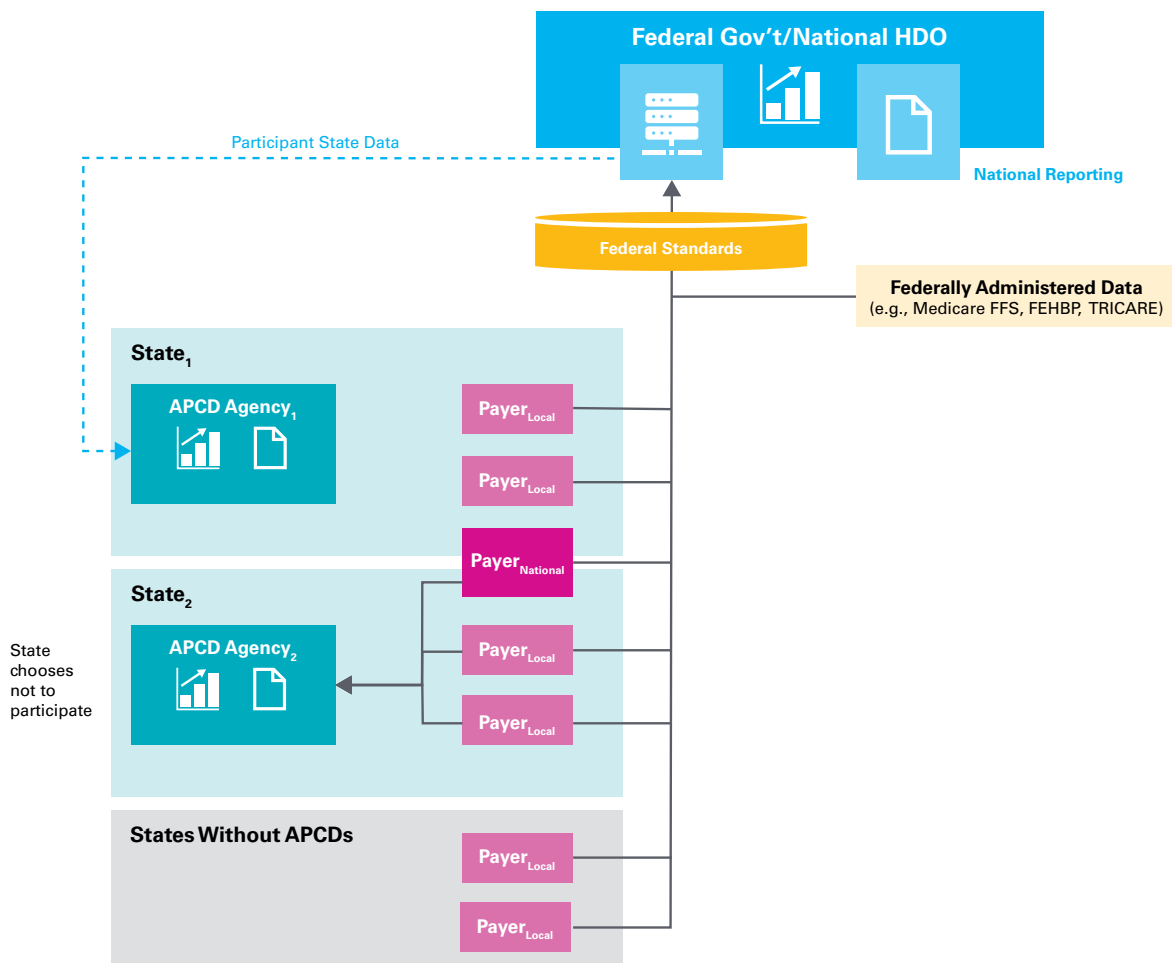
Model Assessment <sup>385</sup>	
Would the model <b>expand APCD data collection to meet national analytic needs?</b>	Limited
<ul style="list-style-type: none"> <li>The model would collect data on behalf of participating APCD states; once established, the collaborative would reduce barriers to entry for new APCD states, potentially increasing national collection.</li> </ul>	
Would the model <b>improve state APCD data completeness?</b>	Mostly
<ul style="list-style-type: none"> <li>The model would establish a common data standard for payer data collection, providing a pathway for ERISA-preempted self-insured data collection.<sup>386</sup></li> <li>The model would not directly address other health system data information gaps (e.g., federal programs, Part 2) data without paired federal intervention.</li> </ul>	
Would the model <b>enhance cross-state data comparability and access?</b>	Yes
<ul style="list-style-type: none"> <li>The model would collect data for participating states using a common data standard, supporting comparative analytics.</li> <li>The model would make cross-state data available through a centralized and transparent application process, allowing for broader access and use.</li> </ul>	
Would the model <b>support state APCD sustainability?</b>	Yes
<ul style="list-style-type: none"> <li>The model would allow participating states to reduce operating budgets to the extent that collaborative data collection and curation fees are less than individual state data collection and curation budgets.</li> <li>The model would offer researchers and other health data purchasers centralized access to cross-state data, potentially generating revenue for the collaborative and participating states.</li> </ul>	
Does the model <b>align with the Guiding Principles?</b> <sup>387</sup>	Limited
<p>The model:</p> <ul style="list-style-type: none"> <li>✓ The model <b>would</b>: <ul style="list-style-type: none"> <li>– Advance health system data as a public good.</li> <li>– Establish a system of cross-state APCD data governance.</li> <li>– Provide multi-state data users and changemakers better access to APCD data.</li> </ul> </li> <li>• The model <b>would partially</b>: <ul style="list-style-type: none"> <li>– Maintain states as APCD data stewards, but would reduce data timeliness by introducing a data intermediary.</li> <li>– Support national health system transparency.</li> <li>– Reduce payer reporting burden in participating states.</li> <li>– Elevate APCD data protections by reducing the number of APCD file exchanges and setting minimum and centralized data collection, management, access, use, and release standards.</li> </ul> </li> <li>✗ The model <b>would not</b>: <ul style="list-style-type: none"> <li>– Meaningfully place the federal government as a partner in resolving data issues—beyond ERISA-preempted self-insured data collection barrier—or as a major prospective data user.</li> </ul> </li> </ul>	

### #1B: Federal Entity

The federal government could directly collect, or collect through an established/designated National HDO, data from payers and TPAs across all states, regardless of the presence of a state APCD.<sup>388</sup> Data could be similar in breadth, scope, and format to APCD files presently collected by states or narrowed to a subset of analytic fields or populations. The National HDO would curate and normalize the payer data it receives and allow state APCDs to request data for their states without charge and in lieu of independent collection. The federal government would allow the National HDO to collect data for the ERISA-preempted self-insured, as well as data on other federally administered lives and health services.

Establishing a National HDO would likely require congressional action and ongoing budget appropriations. The National HDO may be formed and potentially governed in partnership with states with the goal of reducing duplicative data collection with state APCDs and maximizing data use. The National HDO would establish a revenue-sharing model with participating states.

**Exhibit 18: Model 1B, Centralized, Federal Entity**



The National HDO would be responsible for centrally:

- Developing, implementing, and maintaining a common data collection standard and editing process, including working with payers to revise and resubmit submissions, as necessary;
- Creating data submission guides and releasing updates at a pre-determined interval;
- Collecting data from public and private payers and TPAs nationally, including data from federally administered health care coverage and health service programs;
- Storing and managing data in a secure data environment and maintaining cybersecurity protections;
- Compiling, curating, and normalizing payer data for analytic use;
- Distributing analytic-ready data back to participating states;
- Managing a centralized, transparent, and consistent data request and application process;
- Ensuring data release meets minimum thresholds for patient privacy protections; and
- Analyzing national data to support federal, state, and public reporting needs.

States would be able to request regular deliveries of “analytic ready” data from the National HDO without charge and in exchange for sunsetting any existing state payer data submission requirements. State APCD agencies that sunset data collection activities may be able to reallocate budget savings to support greater data use. States without APCDs may choose to invest in APCD-analytic capacity, given the lower barriers to entry.

Payers and TPAs would submit data to the National HDO using a national data standard. The reporting burden on payers and TPAs has the potential to increase substantially, to the extent both the National HDO and state APCD agencies collect data separately—and by different standards.

Federal and state data users would have secure access to National HDO data to support public health, population health, and system transparency use cases. Researchers, purchasers, payers, providers, and other data users would be able to request de-identified data from the National HDO through a single application and application process, reducing barriers to cross-state data access.

Model Assessment <sup>389</sup>	
Would the model <b>expand APCD data collection to meet national analytic needs?</b>	Yes
<ul style="list-style-type: none"> <li>The model would create a national APCD to support analytic use at the state, regional, or national levels.</li> </ul>	
Would the model <b>improve state APCD data completeness?</b>	Yes
<ul style="list-style-type: none"> <li>The model would establish a common data standard for payer data collection, providing a pathway for ERISA-preempted self-insured data collection.<sup>390</sup> To the extent state APCD agencies participate in the model and receive national APCD data, it would fill current data gaps.</li> </ul>	
Would the model <b>enhance cross-state data comparability and access?</b>	Yes
<ul style="list-style-type: none"> <li>The model would collect data using a common data standard, supporting comparative analytics.</li> <li>The model would make cross-state and national data available through a centralized and transparent application process, allowing for broader access and use.</li> </ul>	
Would the model <b>support state APCD sustainability?</b>	Limited
<p>The model would create a federal competitor to state APCDs with the potential to consume local data demand and revenue, unless state APCD agencies agree to divest local data collection responsibilities and rely on data from the National HDO in exchange for revenue-sharing.</p> <p>The model would allow participating states to reduce operating budgets to the extent that National HDO data collection and curation fees are less than individual state data collection and curation budgets. The value of participating states' APCD data would decline, due to increases in data lag (and potentially quality).</p>	
Does the model <b>align with the Guiding Principles?</b> <sup>391</sup>	No
<p>The model:</p> <ul style="list-style-type: none"> <li>✓ The model <b>would</b>: <ul style="list-style-type: none"> <li>Advance health system data as a public good.</li> <li>Provide multi-state data users and changemakers better access to APCD data.</li> <li>Support national health system transparency.</li> </ul> </li> <li>× The model <b>would not</b>: <ul style="list-style-type: none"> <li>Reduce payer reporting burden, and has the potential to significantly increase burden in early years due to data reporting duplication.</li> <li>Establish a system of cross-state APCD data governance, especially in its early years, where a national APCD data collection system has the potential be layered on the existing state-based system, creating reporting duplication and the potential for data misalignment.</li> <li>Maintain states as APCD data stewards. For states choosing to forfeit data collection responsibilities, the introduction of a new data intermediary would reduce data timeliness.</li> <li>Elevate APCD data protections, as new—and potentially duplicative—health system data files are required to be exchanged.</li> <li>Meaningfully place the federal government as a partner in resolving data issues—beyond ERISA-preempted self-insured data collection barrier—or as a major prospective data user.</li> </ul> </li> </ul>	

## Model #2: Decentralized

In a decentralized model, APCD or APCD-like membership and claims data and data ownership would remain distributed (i.e., “in residence” where generated or compiled) and managed locally, whether at the state or payer level, though new pathways—agreements, mechanisms, and methods—for data access would be created to support broader use cases. The model may be advanced in two forms:

### #2A: Uniform State Analytics

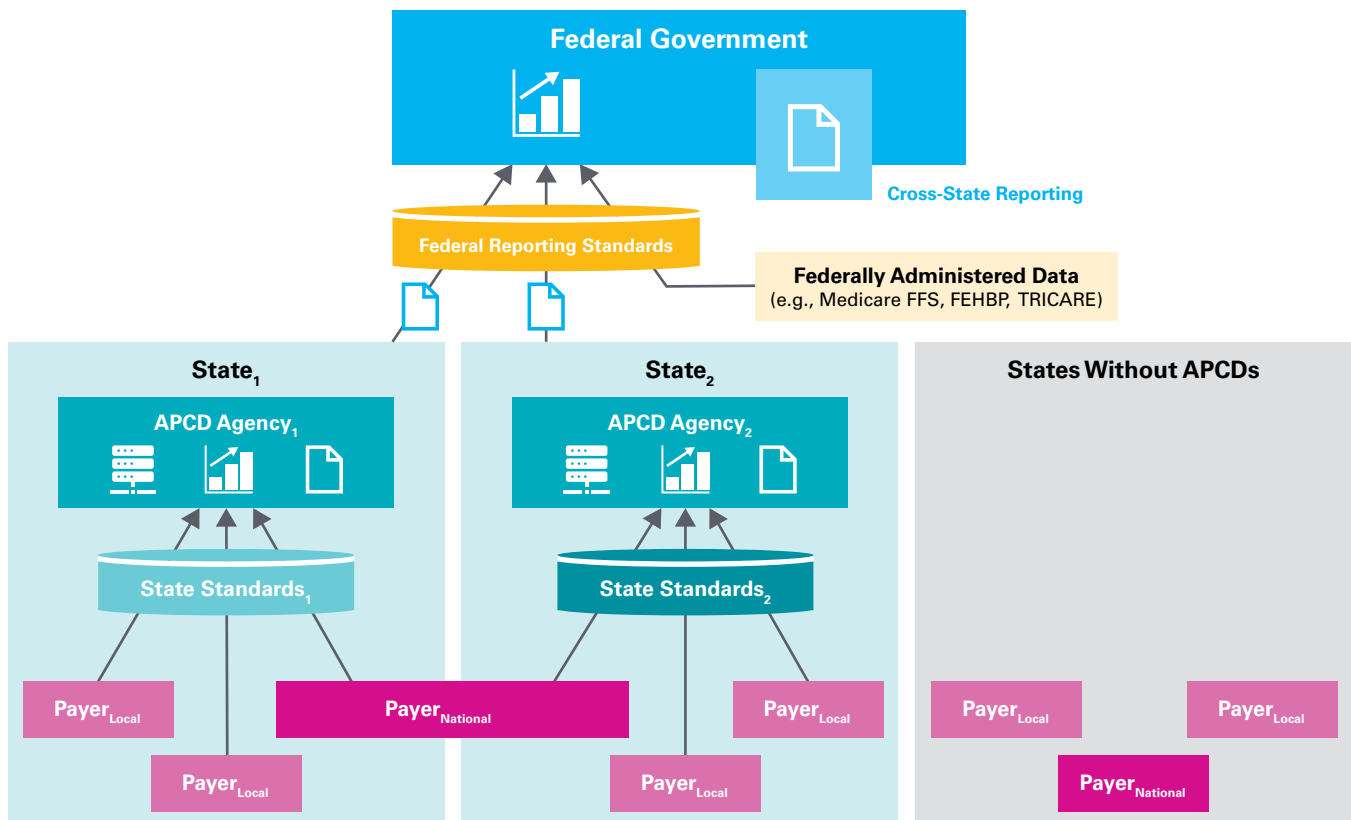
The federal government could establish a data- or information-sharing compact with APCD states wherein, in exchange for financial support, states would provide the federal government with:

- APCD data extracts designed to requested specifications; and/or
- Information and analytic outputs derived by applying a provided, detailed methodology to local APCD data.

The federal government could provide additional funding for participating states to harmonize core “fields of interest” to support its expected analyses.

The model would be similar to that employed by the Patient-Centered Outcomes and Research Institute (PCORI) in its patient outcomes research.<sup>392</sup> State data/information would be collected and combined to support national reporting.

### Exhibit 19: Model 2A, Decentralized, Uniform State Analytics





Federal capacity to support data requests, receipt, compilation, and analysis may be established under existing regulatory authority and potentially within AHRQ, which is presently responsible for similar health data aggregation, analytic, and research functions. Federal data/information solicitations may be developed in partnership with participating states to strengthen methodologies. The federal agency (e.g., AHRQ) would be responsible for:

- Establishing data- and information-sharing agreements with states, including financial terms;
- Working with participating states to translate national policy questions and reporting needs into state data requests with uniform methodologies;<sup>393</sup>
- Providing methodological guidance and technical assistance for state reporting;<sup>394</sup>
- Compiling and analyzing state and federal data to support federal, state, and public reporting; and
- Administering state funding.

Participating states with APCDs would work with the federal agency to develop data request methodologies and support data request fulfillment. Participating states may be asked to share:

- APCD data file extracts;
- APCD summary reports with aggregate information; or
- Information or findings from a complete analysis.

Participating states will follow federal specifications in executing requests to support data/information comparability across states.<sup>395</sup> Participating states would benefit from a new federal revenue source to the extent that new revenue exceeds the marginal costs of meeting new data demands.

Payer and TPA reporting relationships or activities would not be impacted.<sup>396</sup>

The public would gain targeted insights into health system issues to the extent reported on by the federal agency. Data users may have access to a limited amount of new health system data for participating states, to the extent the federal government is willing to and legally can share the data it collects from participating APCD states.

The Uniform State Analytics model would not result in system change, but its implementation could support a “proof of concept”—if needed—to demonstrate the utility of having data from multiple state APCDs.

Model Assessment <sup>397</sup>	
Would the model <b>expand APCD data collection to meet national analytic needs?</b>	Limited
<ul style="list-style-type: none"> <li>• The model would not result in new data collection for or about non-APCD states.</li> <li>• The model would equip the federal government with the ability to collect limited data sets from participating APCD states, though the utility of the extracts and the ability of the stewarding federal agency to share extracts with prospective users would need to be tested.</li> <li>• The model would provide the federal government with targeted insights into national health system issues, to the extent issues are represented in information shared by participating states.</li> </ul>	
Would the model <b>improve state APCD data completeness?</b>	No
<ul style="list-style-type: none"> <li>• The model would not impact the completeness of state APCD data.</li> <li>• The model could improve cross-state APCD data quality to the extent the stewarding federal agency engages with participating states to share findings and anomalies from the cross-state normalization process (e.g., identification of missing populations or claims data based on claims-volume benchmarking).</li> </ul>	
Would the model <b>enhance cross-state data comparability and access?</b>	Limited
<ul style="list-style-type: none"> <li>• The model could improve cross-state APCD data harmonization over time, to the extent the federal government uses financial incentives to push for field harmonization.</li> <li>• The model would provide APCD states with common methodologies to use—and initial results to build from—to track health system concerns.</li> </ul>	
Would the model <b>support state APCD sustainability?</b>	Limited
<ul style="list-style-type: none"> <li>• The model would provide a valuable revenue source for state APCD agencies without requiring major initiation or ongoing implementation costs.</li> <li>• The model would further demonstrate the ability of state APCDs to answer key policy, program, market, and population health questions—and proven methodologies to answer related questions—potentially generating greater local interest and data demand.</li> </ul>	
Does the model <b>align with the Guiding Principles?</b> <sup>398</sup>	Limited
<p>The model:</p> <ul style="list-style-type: none"> <li>✓ The model <b>would</b>: <ul style="list-style-type: none"> <li>– Maintain states as APCD data stewards.</li> </ul> </li> <li>• The model <b>would partially</b>: <ul style="list-style-type: none"> <li>– Support national health system transparency.</li> <li>– Advance health system data as a public good.</li> <li>– Meaningfully engage the federal government as a major prospective data user, but not as a partner in resolving data issues.</li> </ul> </li> <li>× The model <b>would not</b>: <ul style="list-style-type: none"> <li>– Establish a system of cross-state APCD data governance.</li> <li>– Provide multi-state data users and changemakers better access to APCD data.</li> <li>– Reduce payer reporting burden in participating states.</li> <li>– Elevate APCD data protections.</li> </ul> </li> </ul>	

## #2B: Uniform Payer-Based Data

The federal government, in partnership with payers/TPAs and states, could establish a national APCD standard which payers would then use to develop APCD files for their respective memberships and maintain in their internal protected data environments. Federal and state APCD agency authorized users would be granted permission to query payer data to construct consolidated and customized APCD files, as needed. A “Uniform Payer-Based Data” model could eliminate the need for payers to develop and regularly transmit APCD files to federal/state recipients in accordance with their varied submission requirements. As recommended by United Healthcare during SAPCDAC hearings, in such an arrangement, payers could employ modern FHIR API standards—now a mainstay in federal data-sharing and interoperability requirements<sup>399</sup>—to provide federal/state recipients timely and efficient access to membership and claims data.<sup>400</sup> The model would be similar to the ACA External Data Gathering Environment (EDGE) and the model proposed by the Blue Cross Blue Shield Association and AHIP at the SAPCDAC hearings.<sup>401</sup>

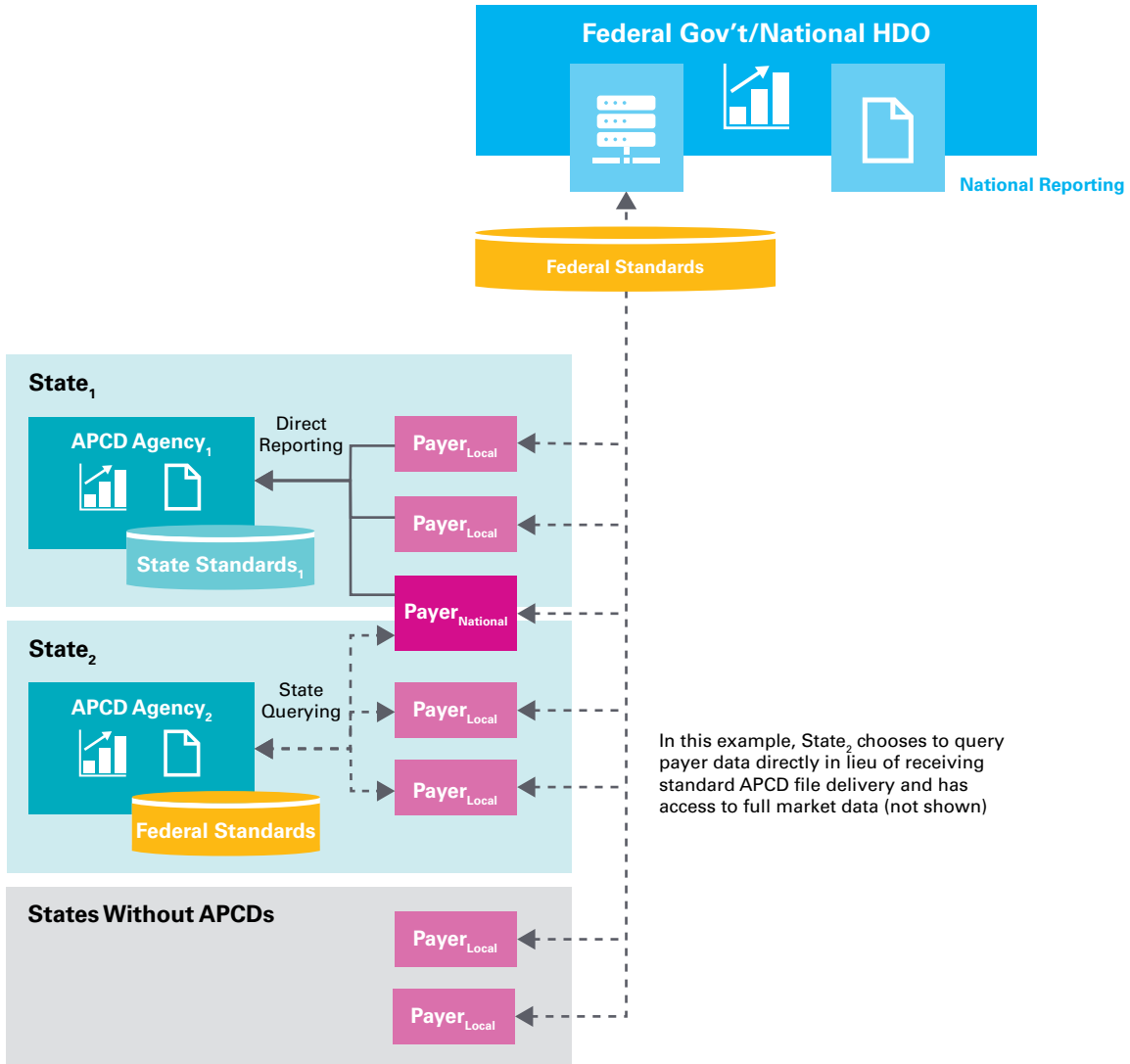
The federal government would work with payers/TPAs and states to support the implementation of the decentralized data model, including establishing a federal-state data governance and change-management process.

State with APCDs would need to choose whether to participate in the model, which would require them to actively collect payer data from individual payer systems, instead of receiving standardized files on a regular cadence. The federal government could incent participation by requiring payers/TPAs provide full population data in the APCD files they make available internally to states that sunset direct reporting requirements.

To participate in direct payer data collection, the federal government would need to establish centralized data collection, curation, and analytic capacity. This would be an added component to—not a prerequisite of—implementing this model.

This data collection model has the potential to expand national and state data access, but would not directly create new federal/national or state analytic capacity. Further, and as strongly cautioned by one report, the model could have drawbacks, including divesting data ownership—and potential discretion over data access and use—to private payers, instead of state agencies working on behalf of the public good.<sup>402</sup> State/federal data users would also be newly responsible for proactively notifying payers of failed files instead of simply denying submissions, shifting the burden of initial quality checks.<sup>403</sup>

Exhibit 20: Model 2B, Decentralized, Uniform Payer-Based Data



Payers/TPAs would be responsible for:

- Developing up-to-date and complete APCD files for protected storage in their data environments;
- Maintaining data permissions and supporting data access;
- Providing state/federal technical assistance to access data pulled from their data environments; and
- Revising and reposting data, where errors were identified by any state(s) and notifying the others via a change log.

It is unlikely that many payers/TPAs will have the near-term ability to participate in this type of exchange.<sup>404</sup> Smaller, regional payers, and those that do not presently need to comply with federal interoperability requirements may also not be prepared to participate.

The federal government and states choosing to participate in direct payer data collection would be newly responsible for:

- Collecting standardized data from participating payers through new methods;
- Actively providing early-round feedback to payers, where posted files do not meet validation checks; and
- Curating and normalizing payer data collected through this method with other payer data that may still be reported through manual processes.

The federal government/states would also need to develop processes and data use agreements with payers that would allow for subsequent data extract distribution to users.

Model Assessment <sup>405</sup>	
Would the model <b>expand APCD data collection to meet national analytic needs?</b>	<b>Mostly</b>
<ul style="list-style-type: none"> <li>• The model would provide the federal government—or a National HDO established on the government’s behalf—access to national health system data to respond to pressing data needs. A full national APCD data set could be created, as needed.</li> <li>• The model would allow non-APCD states to participate in payer data collection to respond to health system questions without investing in significant data collection and analytic capacity.</li> <li>• The model would add significant data governance and legal complexity in determining permissions.</li> </ul>	
Would the model <b>improve state APCD data completeness?</b>	<b>Mostly</b>
<ul style="list-style-type: none"> <li>• The model would establish a common data standard for payer APCD data, providing a pathway for ERISA-preempted self-insured data collection.<sup>406</sup> States would be required to sunset existing payer reporting and modify internal operations to support the model.</li> </ul>	
Would the model <b>enhance cross-state data comparability and access?</b>	<b>Limited</b>
<ul style="list-style-type: none"> <li>• The model would require a national APCD data standard for payer file development. It is unclear how many states would participate in the model. If state participation is low, it could result in duplicative reporting and the persistence of APCD file development using different standards.</li> <li>• The model may allow users to request APCD data—pulled from specific payers—from the federal government or state APCD agencies.</li> </ul>	
Would the model <b>support state APCD sustainability?</b>	<b>No</b>
<ul style="list-style-type: none"> <li>• The model could increase state APCD agency costs, should they wish to continue collecting full APCD files, requiring active querying to collect data that was previously, actively reported.</li> <li>• The model would not lend itself to revenue-sharing arrangements for state APCD data.</li> </ul>	
Does the model <b>align with the Guiding Principles?</b> <sup>407</sup>	<b>Limited</b>
<p>The model:</p> <ul style="list-style-type: none"> <li>✓ The model <b>would</b>: <ul style="list-style-type: none"> <li>– Advance health system data as a public good.</li> <li>– Support national health system transparency.</li> <li>– Meaningfully engage the federal government as a partner in resolving data issues and as a major prospective data user.</li> </ul> </li> <li>• The model <b>would partially</b>: <ul style="list-style-type: none"> <li>– Establish a system of cross-state APCD data governance.</li> <li>– Reduce payer reporting burden in participating states.</li> <li>– Provide multi-state data users and changemakers better access to APCD data, though a process would need to be defined and implemented.</li> </ul> </li> <li>× The model <b>would not</b>: <ul style="list-style-type: none"> <li>– Maintain states as APCD data stewards, creating new burdens for data access.</li> <li>– Elevate APCD data protections, as the volume and scale of external queries—between payers and state APCD agencies—would increase exponentially, potentially creating new risks to patient privacy.</li> </ul> </li> </ul>	

### Model #3: Partnership

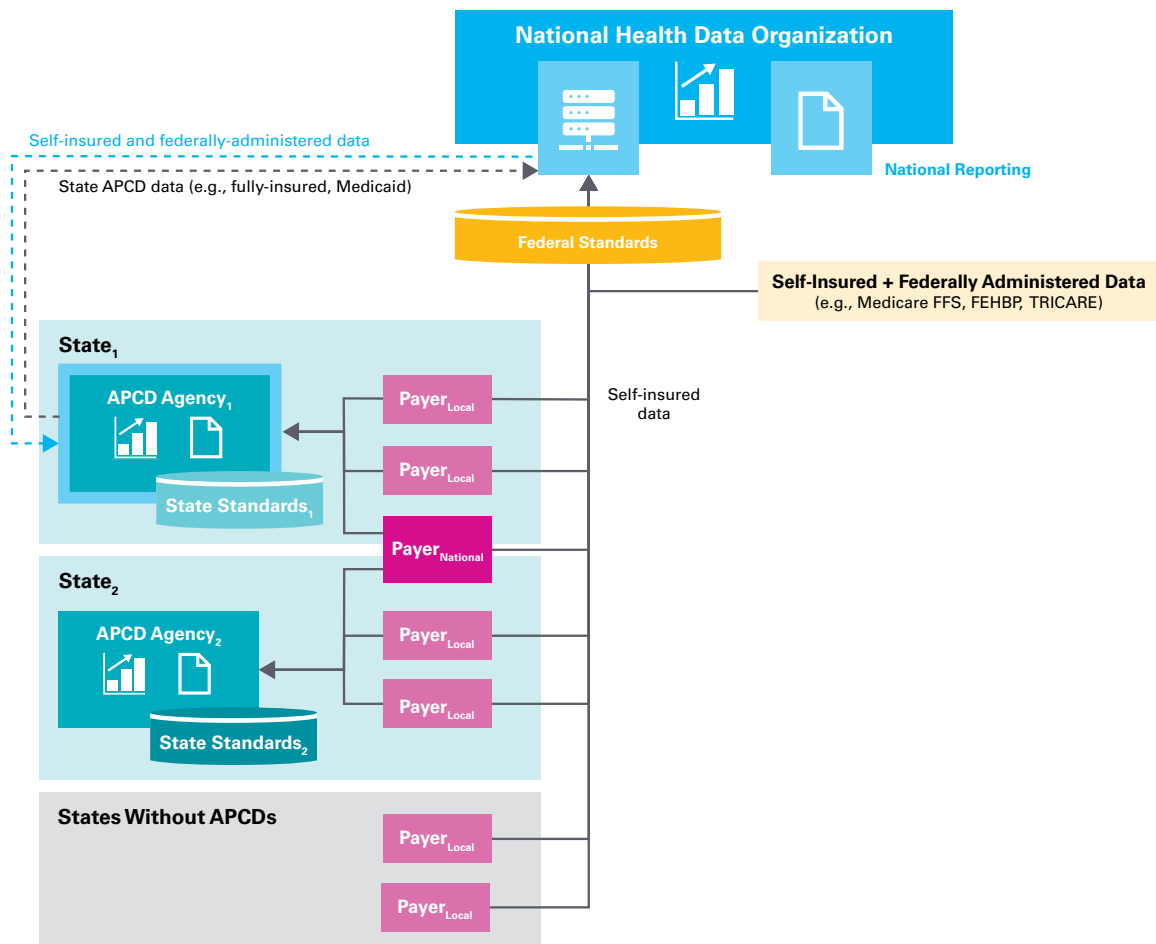
In a partnership model, state HDOs would retain ownership of existing APCD data, and have the option of engaging in a reciprocal exchange with a new National HDO to address their data gaps. The model may be advanced in two forms:

#### #3A: Federal-State Data Trade (LHCC Act Proposal)

Similar to the model offered in the LHCC Act to bipartisan support, the federal government would establish a National HDO to centrally collect, compile, and curate: federally regulated (e.g., self-insured) data from payers/TPAs using a common national APCD data standard; and federally administered data from CMS and other agencies.

States with APCDs may request National HDO data without charge<sup>408</sup> to support local use cases, in exchange for sharing local APCD data (e.g., fully insured, Medicaid) with the National HDO. The exchange would eliminate state APCDs' self-insured and federal program data gaps.<sup>409</sup>

Exhibit 21: Model 3A, Partnership, Federal-State Data Trade



The National HDO would curate and normalize the data it receives, creating a national APCD that comprises complete self-insured and federally available membership and claims data, and complete market data for states participating in the reciprocal data-sharing arrangement.<sup>410</sup>

Establishing a federal National HDO would likely require congressional action and ongoing budget appropriations. The National HDO may be formed and potentially—in a deviation from the LHCC Act proposal—governed in partnership with states with the goal of reducing duplicative state APCD data collection and maximizing data utility. The National HDO would be responsible for centrally:

- Developing, implementing, and maintaining a common national APCD data standard;
- Creating data submission guides and releasing updates at a pre-determined interval;
- Collecting self-insured data from public and private payers/TPAs nationally, as well as data from federally administered health care coverage and health service programs;
- Maintaining a data editing process, including working with payers/TPAs to revise and resubmit submissions, as necessary;
- Storing and managing data in a secure data environment and maintaining cybersecurity protections;
- Compiling, curating, and normalizing payer data for analytic use;
- Distributing analytic-ready data back to participating states;
- Managing a centralized, transparent, and consistent data request and application process;
- Ensuring data release meets minimum thresholds for patient privacy protections; and
- Analyzing national data to support federal, state, and public reporting needs.

In this model, payers and TPAs would submit different segments of their administrative data to states with APCDs and the National HDO. The reporting burden on payers/TPAs would likely increase as a new data trading partners is established (the National HDO) to collect data by a separate national standard.<sup>411</sup>

The National HDO could establish a fee schedule for data access, and share revenues generated from sales of participating states' data back with states.

Federal, state, and other data users would have direct access to a quasi-national APCD comprising all self-insured and federally administered data, and state data where the National HDO has a data-sharing relationship. Data users would be able to request data from the National HDO through a single application and application process.



Model Assessment <sup>412</sup>	
Would the model <b>expand APCD data collection to meet national analytic needs?</b>	<b>Mostly</b>
<ul style="list-style-type: none"> <li>The model would establish a quasi-national APCD with complete self-insured and federally administered program data, and complete market data for states with APCDs that participate in its reciprocal data sharing relationship.</li> </ul>	
Would the model <b>improve state APCD data completeness?</b>	<b>Mostly</b>
<ul style="list-style-type: none"> <li>The model would establish a common data standard for self-insured APCD data, providing a pathway for ERISA-preempted self-insured data collection.<sup>413</sup> States could receive self-insured data and data for federally administered programs in exchange for the data they steward. Not all states with APCDs would choose to participate in the exchange.</li> </ul>	
Would the model <b>enhance cross-state data comparability and access?</b>	<b>Limited</b>
<ul style="list-style-type: none"> <li>The model would not enhance cross-state APCD comparability, as proposed. The national APCD data standard would only be used for the collection of self-insured data from payers/TPAs by the National HDO (adoption of the standard by states interested in receiving access to the data could be introduced, but might be a disincentive to participation). Some natural harmonization around a common APCD standard, even if only for self-insured data, could be possible if states are engaged in the standard-development process.</li> </ul>	
Would the model <b>support state APCD sustainability?</b>	<b>Limited</b>
<ul style="list-style-type: none"> <li>The model would provide participating states with access to new self-insured and federally administered data, which could support valuable use cases, strengthening APCD utility.</li> <li>The model could create a national source for state APCD data with a revenue-sharing model for fees generated from state APCD data.</li> </ul>	
Does the model <b>align with the Guiding Principles?</b> <sup>7414</sup>	<b>Limited</b>
<p>The model:</p> <ul style="list-style-type: none"> <li>✓ The model <b>would</b>: <ul style="list-style-type: none"> <li>– Maintain states as APCD data stewards.</li> <li>– Advance health system data as a public good.</li> <li>– Support national health system transparency.</li> <li>– Meaningfully engage the federal government as a partner in resolving data issues and as a major prospective data user.</li> </ul> </li> <li>• The model <b>would partially</b>: <ul style="list-style-type: none"> <li>– Provide multi-state data users and changemakers better access to APCD data.</li> </ul> </li> <li>× The model <b>would not</b>: <ul style="list-style-type: none"> <li>– Establish a system of cross-state APCD data governance.</li> <li>– Reduce payer reporting burden in participating states.</li> <li>– Elevate APCD data protections.</li> </ul> </li> </ul>	

### #3B: Federally Facilitated State Data Partnership

Similar to the federal AHRQ HCUP model,<sup>415</sup> the federal government and state APCD agencies would work together to establish a mutually beneficial data exchange arrangement that would provide participating states and a National HDO with complete health system information. The model has four components:

**(1) National HDO:** The federal government would establish a National HDO that would be responsible for centrally collecting, compiling, and curating APCD data from states participating in its data exchange partnership. The National HDO would also be responsible for collecting federally administered data for distribution to participating states. The National HDO would be jointly governed by federal and state leaders and consumer privacy representatives.

**(2) National APCD Data Standard:** The National HDO would establish a national APCD data standard that would support the collection of APCD data across all payer types, lines of business, and APCD file types. The National HDO would also establish baseline data privacy and security standards for states participating in its data exchange program.

**(3) State Choice for Program Participation and Expanded APCD Data Collection:** States would choose whether to participate in an APCD data sharing partnership with the National HDO. Participation would allow states to:

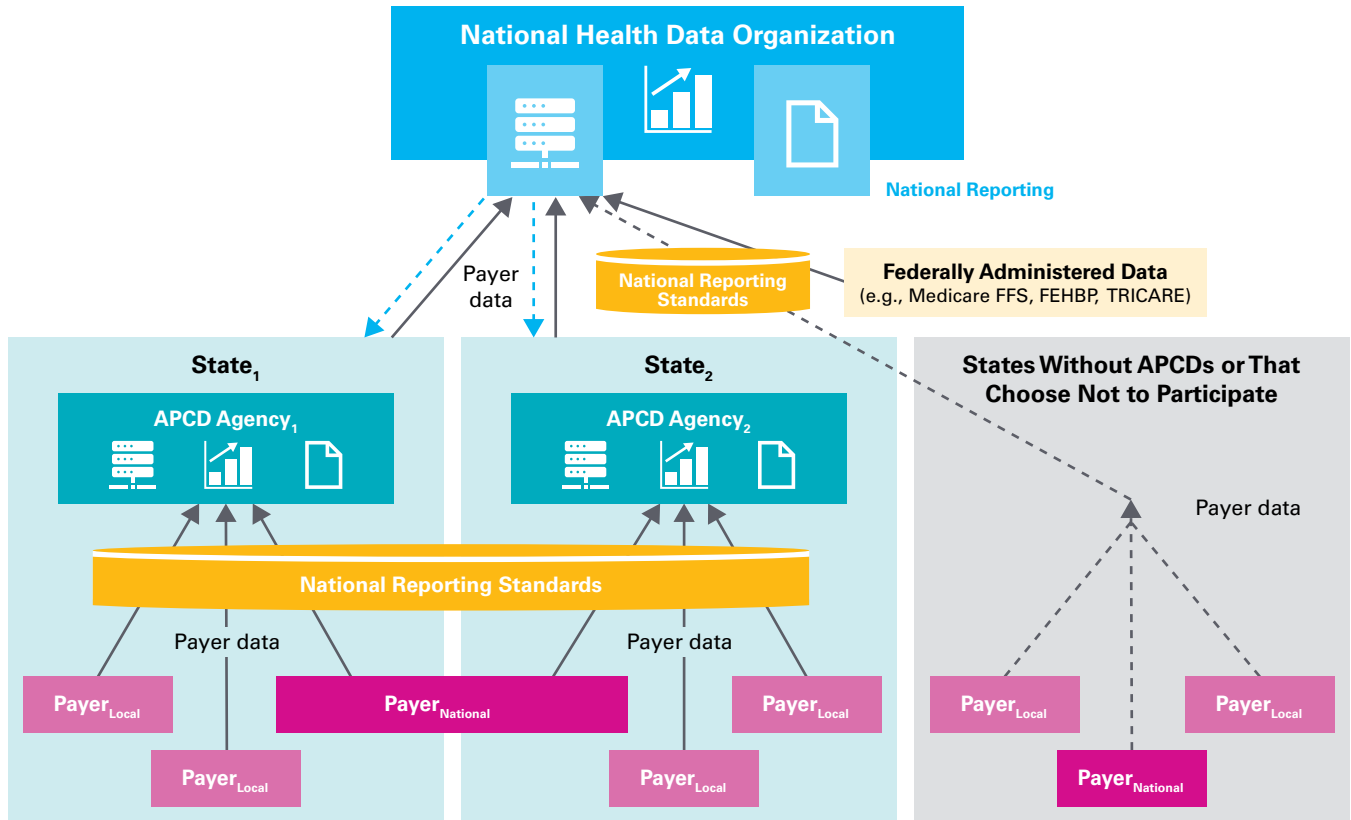
- Collect full market data from their locally operating payers/TPAs, including ERISA-preempted self-insured data, using the national APCD data standard.
- Access federally administered data through file distributions from the National HDO.
- Potentially access federal funding support for local HDO operations (not discussed or assessed in this operationally focused section).

In exchange, states would adopt the national APCD data standard for their payer/TPA data collections and share complete APCD files with the National HDO. States may need to modify local regulations to participate. This model would allow states to maintain full ownership of their local APCD data.

**(4) National APCD Gap Fill:** For states that do not have an APCD or that choose not to participate in the data exchange, the National HDO would collect data directly from those states' payers/TPAs to support national benchmarking and reporting.

The model would result in the adoption of a national APCD data standard, state APCDs—in states that choose to participate in the national APCD data exchange—with more complete information to support local use cases without losing data timeliness, and a new national APCD with complete market information.

Exhibit 22: Model 3B, Partnership, Federally Facilitated State Data



Establishing a National HDO would likely require Congressional action and ongoing budget appropriations. As with most of the models proposed and as discussed in the “Model Assumptions” section, the model would also require the confirmation of federal authority—or the granting of new authority—to allow ERISA-preempted self-insured data collection by a common data standard, and for that collection to be permitted for an entity other than DOL (i.e., states).

The National HDO would be responsible for centrally:

- Developing, implementing, and maintaining a common national APCD data standard;
- Creating data submission guides and releasing updates at a pre-determined interval;
- Collecting data from states, federally administered programs, and payers and TPAs in non-participating states in alignment with national APCD standards, maintaining edit checks, and working with submitters to review, revise, and request resubmissions;
- Compiling, curating, and normalizing data for analytic use;
- Sharing federally administered program data with participating state APCD agencies;
- Storing and managing data in a secure data environment and maintaining cybersecurity protections;
- Managing a centralized, transparent, and consistent data request and application process;
- Ensuring data release meets minimum thresholds for patient privacy protections; and
- Analyzing national data to support federal, state, and public reporting.

The National HDO could establish a fee schedule for data access, and share revenues generated from sales of participating states' data back with states. The National HDO may be responsible for overseeing a federal grant program for state HDOs/state APCD agencies. The National HDO may support state APCD data collection at cost, if desired.

State APCD agencies that choose to participate in the program would be newly responsible for:

- Aligning with common national APCD data standards;
- Collecting ERISA-preempted self-insured data;
- Consuming and integrating new federally administered program data;
- Complying with new national APCD data privacy and security standards;
- Submitting data to the National HDO and working collaboratively with the National HDO to resolve data issues.

State APCD agencies may also choose to outsource local APCD data collection responsibilities to the National HDO. The responsibilities of state APCD agencies that choose not to participate in the program would not change.

Payers and TPAs would continue to submit data to APCD states, though submission standards would be harmonized across states participating in the National HDO data exchange program. Payers and TPAs may be newly responsible for submitting data to the National HDO in states that do not have APCDs. The number of submission targets may decrease over time if states choose to outsource data collection to the National HDO.

Federal data users would have access to national health system data to support public health, population health, and system transparency use cases. Other data users, including researchers, purchasers, consumers, payers, and providers, would be able to acquire data from the National HDO through a single application and application process, reducing barriers to cross-state data access.

Model Assessment <sup>416</sup>	
Would the model <b>expand APCD data collection to meet national analytic needs?</b>	Yes
<ul style="list-style-type: none"> <li>The model would establish a complete national APCD.</li> </ul>	
Would the model <b>improve state APCD data completeness?</b>	Mostly
<ul style="list-style-type: none"> <li>The model would establish a common data standard for payer data collection, providing a pathway for ERISA-preempted self-insured data collection for participating states.<sup>417</sup></li> <li>The model would allow participating states to access data for federally administered programs.</li> </ul>	
Would the model <b>enhance cross-state data comparability and access?</b>	Mostly
<ul style="list-style-type: none"> <li>The model would establish a national APCD data standard, which would be used by the National HDO and participating states. Not all states would choose to participate and adopt the standard.</li> <li>The model would make cross-state data available through a centralized and transparent application process, allowing for broader access and use.</li> </ul>	
Would the model <b>support state APCD sustainability?</b>	Mostly
<ul style="list-style-type: none"> <li>The model would allow participating states to access new self-insured and federally administered data, strengthening APCD utility.</li> <li>The model would create a national source for state APCD data with a revenue-sharing model for fees generated from state APCD data.</li> <li>The model would allow states to outsource data collection responsibilities to the National HDO at potentially lower costs than they presently incur (optional).</li> </ul>	
Does the model <b>align with the Guiding Principles?</b> <sup>418</sup>	Mostly
<p>The model:</p> <ul style="list-style-type: none"> <li>✓ The model <b>would</b>: <ul style="list-style-type: none"> <li>Maintain states as APCD data stewards.</li> <li>Advance health system data as a public good.</li> <li>Establish a system of cross-state APCD data governance.</li> <li>Provide multi-state data users and changemakers better access to APCD data.</li> <li>Support national health system transparency.</li> <li>Elevate APCD data protections by setting minimum and centralized data collection, management, access, use, and release standards.</li> <li>Meaningfully engage the federal government as a partner in resolving data issues—beyond ERISA-preempted self-insured data collection barrier—or as a major prospective data user.</li> </ul> </li> <li>• The model <b>would partially</b>: <ul style="list-style-type: none"> <li>Reduce payer reporting burden in participating states, though some states may choose not to participate, resulting in duplicative submissions. Payers/TPAs would also be newly responsible for reporting to the National HDO with data from non-APCD states.</li> </ul> </li> </ul>	

## D. Recommended Model

Model 3B, “Federally Facilitated State Data Partnership,” meets the most criteria in the model assessment (Exhibit 23). Model 3B:

- Establishes a national APCD to meet cross-state, regional, and national health system data needs;
- Establishes new, shared governance for our nation’s health system data between federal, state, and consumer privacy representatives;
- Improves state APCD data completeness for states that choose to participate;
- Improves cross-state data comparability by allowing access to a harmonized national data set and instilling data standardization across participating state APCDs;
- Supports state APCD sustainability by equipping them with more complete market data and allowing revenue sharing from national APCD purchases; and
- Aligns with most of the guiding principles for model design, including, importantly, preserving state APCD data stewardship.

**Exhibit 23: National APCD Operating Model Assessment Results**

Model Assessment	Models					
	(1) Centralized		(2) Decentralized		Partnership	
	(1A) State Collaborative	(1B) Federal Entity	(2A) Uniform State Analytics	(2B) Payer Open Data Access	(3A) Federal-State Data Trade	(3B) Federally Facilitated State Data Partnership
Would the model <b>expand APCD data collection to meet national analytic needs?</b>	Limited	Yes	Limited	Mostly	Mostly	Yes
Would the model <b>improve state APCD data completeness?</b>	Mostly	Yes	No	Mostly	Mostly	Mostly
Would the model <b>enhance cross-state data comparability and access?</b>	Yes	Yes	Limited	Limited	Limited	Mostly
Would the model <b>support state APCD sustainability?</b>	Yes	Limited	Limited	No	Limited	Mostly
Does the model <b>align with key guiding principles</b> <sup>7419</sup>	Limited	No	Limited	Limited	Limited	Mostly

However, Model 3B is not without shortcomings. For example, it does not result in total state APCD harmonization, leaving it to states to determine whether they would like to participate in national standardization or not. It also requires the National HDO to rely on state data submissions, which will result in data lag. The National HDO would be required to have a sizable, complex, and changing scope as it serves as

a “wrap” for state APCD data collection, with state participation changing over time. As with other models, its implementation would require substantive investment by the federal government, both for the establishment of a National HDO, as well as to support states in implementing participation requirements, for which they might not otherwise have funding.

Model 1A could also meet many of the desired outcomes of a national model, preserving state ownership, potentially without the need for federal intervention. It would, however, leave holes in state and national APCD data collection.

Model 1B would be more straightforward recommendation in many ways, having a single federal entity/National HDO to collect APCD data from payers/TPAs nationally, then redistributing collected and harmonized data to participating states. While it would create a duplicative data system at the start, many states would likely, eventually, opt to receive data directly from the National HDO in lieu of continuing to support their own costly data collections—especially if federal data collection was more complete (e.g., included ERISA-preempted self-insured data) and participation provided states access to revenue sharing from national data purchases. However, despite the model’s efficiency—arguably the most efficient data exchange ecosystem presented—it would violate a core principle: maintaining state data ownership. This principle does not just represent a preference of state APCD data leaders, but also reflects technical and political realities that must be bridged: the difference between recommendations that are theoretically optimal and those that are practically feasible. For example, in Model 1B:

- The timeliness of the APCD data states receive would deteriorate, as the federal entity/National HDO would serve as a new data intermediary with payers/TPAs. Data delays could potentially range from a few months or over a year—as with T-MSIS data—as the federal entity/National HDO conducts its own edit checks with payers/TPAs. Data delays could severely impact existing state data use.
- The quality of the APCD data states receive could deteriorate, as state APCD staff—who are currently responsible for maintaining data quality edits and adjudication—would no longer be directly involved in data intake and review. The federal entity/National HDO would not have local market perspective to check the individual state data they receive.
- Threshold political questions would likely be raised at the state- and federal-levels about a federal entity/National HDO unilaterally exerting its federal authority—and essentially force state compliance—to achieve national data collection objectives.

Model 1B could arguably serve as the most efficient and expedient national health system data solution, but it likely ignores key technical and political realities that would make getting key stakeholder buy-in questionable.

Model 2A could be a good starting opportunity to demonstrate the value of cross-state APCD data access, but would not structurally resolve any of our nation’s health system data gaps.

Model 2B would deviate significantly from the stated needs of states and health care purchasers, changing the national APCD model to decentralize data back to the payers. While this, in theory,

Model 1B could arguably serve as the most efficient and expedient national health system data solution, but it likely ignores key technical and political realities that would make getting key stakeholder buy-in questionable.

could present some federal and state data users with more ready access to payer data, it would significantly expand the transmission of large health system data files nationally and may limit use by many state HDOs. It could also impact the quality of the “APCD” data maintained locally by payers and make it more difficult for states to consolidate cross-market data.

Model 3A has been proposed to bipartisan support. However, it could introduce a national APCD model with persistent data gaps for states that choose not to participate in the federal-state data exchange. It also fails to include states in the data governance process.



## VI. Federal and State APCD Action Plan: Recommendations to Realize the Promise of APCDs

The implementation of an effective and sustainable national APCD model that aligns with the guiding principles—recommended in this report as the **Federally Facilitated State Data Partnership** (see Section V.D)—will require federal and state stakeholders to work together to establish a:

1. **National HDO** that is viewed as a trustworthy, independent, and protective steward of the nation’s health care administrative data.
2. **Federal-state governance partnership** to oversee and direct National HDO activities, including the alignment of uniform data standards and practices across participating states.
3. **Plan to resolve ERISA reporting barriers** to ensure states have access to the data necessary to oversee their markets, and purchasers (and other users) have data to make comparisons across markets.
4. **Source of federal health data funding for states** to support model implementation and sustain permanent and robust state or regional health data collection and analytic infrastructure.
5. **National compact on APCD data privacy and security** to set baseline privacy and security protections for the National HDO and participating states.

This section offers specific actions for state and federal leaders for how each of these requirements may be realized.

## Action 1: Establish a National Health Data Organization

The formal establishment of a National HDO and its data collection authority may require federal legislation similar to that put forth in the LHCC Act.<sup>420</sup> Legislation may charge AHRQ, in collaboration with ASPE and DOL, with establishing or designating a National HDO—similar to ONC’s appointment of the Sequoia Project as the national “Recognized Coordinating Entity”<sup>421</sup>—administering and distributing funding to the organization. AHRQ would be uniquely positioned to support the undertaking, with a mission focused on “improving the safety and quality of healthcare for all Americans” and direct experience collecting, compiling, and curating a national data set from state reporting through its HCUP program.<sup>422</sup> ASPE would serve as a strong agency partner to AHRQ, providing strategic, legislative planning, and cross-departmental coordination support, including helping negotiate new federal data-sharing arrangements (e.g., Medicare data from CMS, veterans’ health data from the VHA) and setting a national APCD data standard, a likely prerequisite for the collection of ERISA-preempted self-insured data.

As proposed in the LHCC Act, the sponsoring agency—herein proposed as AHRQ—would competitively procure a vendor that would be responsible for fulfilling National HDO responsibilities, in coordination with the National HDO Governance Entity (see [Action 2](#)).<sup>vi</sup> Explicitly procuring private organization(s) to serve in this role would mitigate concerns about unfettered federal access to collected data and would ensure the National HDO is subject to greater accountability, making the National HDO more politically viable (see callout).

AHRQ would be responsible for contracting with the selected National HDO, supporting National HDO vendor transitions, and supporting the National HDO Governance Entity, in instances where the National HDO cannot fulfill this responsibility. National HDO oversight and direction, however, would be the responsibility of the Governance Entity, as described in [Action 2](#).

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<sup>vi</sup> The National HDO may comprise multiple organizations working collaboratively under one contract. Any procurement may require that the National HDO collect, store, manage, and report on data in a way that may be transferrable to another vendor in the future to maintain the quality of services delivered through competitive incentives.

### The Importance of National HDO Independence

Establishing a national HDO that is external to the federal government and jointly governed by a federal and state board (see [Action 2](#)) by a set of public data privacy standards (see [Action 5](#)), has several important benefits:

- **Trust:** Americans' trust in our public institutions remains at historically low levels.<sup>423</sup> Establishing a transparently governed and operated non-federal organization to steward the nation's health system data will provide federal and state policymakers, and the Americans they represent, with greater assurance that the organization and its data will remain protected from the nation's changing politics and policies and used only for specified purposes. The national HDO will be regularly and publicly accountable to its diverse board, comprising state, federal, and consumer privacy representatives.
- **Operational Effectiveness:** State APCD agency leaders expressed reticence in depending on a federal agency for the collection and delivery of high quality and timely data. While the quality and timeliness of federal data releases have improved in recent years (e.g., CMS' T-MSIS), state concerns remain. State stakeholders strongly advocated for a federally contracted entity that would be jointly accountable to federal and state stakeholders for providing efficient upstream collections (e.g., APCD data collected from states) and downstream distributions (e.g., federally administered data).
- **Operational Efficiency:** Many public and private stakeholders noted that a federally procured, private sector national HDO could also be operationally and financially more efficient than one established within a federal agency. Many private sector HDOs presently have the technology and capacity to scale and support the establishment of a protected national health data repository, and deep experience with the type of secure data transactions that will be needed to support exchanges among states, payers/TPAs, and the National HDO. Private sector HDOs would also likely be able to recruit—or redeploy—needed technical and legal/data privacy talent more quickly than a federal agency to meet organizational needs as they arise.

Establishing a transparently governed and operated non-federal organization to steward the nation's health system data will provide federal and state policymakers, and the Americans they represent, with greater assurance that the organization and its data will remain protected from the nation's changing politics and policies and used only for specified purposes.

The establishment of a national HDO will require federal and state political buy-in, and—most importantly—the trust of the American people. Explicitly removing oversight and operations of the national HDO from the federal government and its executive branch would likely maximize the possibility of its implementation.

## National HDO Responsibilities and Functions

The National HDO would be responsible for supporting the following functions under the oversight of its Governance Entity (see [Action 2](#)):

**(1) Develop and manage national APCD data standard:** The National HDO would be responsible for supporting the development, implementation, and maintenance of a national APCD data collection standard. As discussed in greater detail in Section [IV.2.1](#), this would comprise:

- Procuring an expert SDO to staff standards development and management.
- Support establishment of a National APCD Standards Advisory Group (APCD SAG)—comprised of federal, state, payer/TPA, Medicaid, and data user representatives—to design a national APCD data standard that builds from the CDL and reflects current industry transaction and coding standards, as well as the analytic needs of data users.<sup>424</sup>
- Overseeing and managing the national APCD standards development process, including any public comment periods, and submitting draft-final standards to the National HDO Governance Entity and DOL for review and approval.
- Support the APCD SAG and the NCVHS in developing and implementing a process by which the national APCD data standard would be governed.<sup>425</sup>
- Support implementation of the national APCD data standard by participating states as well as the payers/TPAs and federal programs that would be directly submitting to the National HDO. The National HDO would provide data submitters with technical support and implementation funding (see [Action 4](#)).

The National HDO would document national APCD standards in data submission guides and data user manuals, among other communications.

**(2) National data collection and curation:** The National HDO would be responsible for collecting APCD data from participating APCD states, payers and TPAs in non-participating states, and federal programs.<sup>426</sup> The National HDO would be responsible for—with input from participating states—setting national APCD data submission standards and edits, then reviewing data submissions against those standards and edits, checking for: internal consistency, cohesiveness (i.e., cross-file linkage), and completeness, and external quality assurance, including reasonableness and accuracy checks.

**(3) National data normalization and analytic preparations:** The National HDO would be responsible for normalizing APCD data across states to prepare it for analytic use. The National HDO would develop and apply key analytic fields to consolidated data, including master member identifiers,<sup>427</sup> master provider identifiers, and other value-added fields (e.g., clinical groupers). The National HDO may strip member identifiers and other sensitive information from the data it receives before migrating it to an analytic environment.

**(4) National data analytics and reporting:** The National HDO would be responsible for executing the Governance Entity’s priorities for analytics and reporting, developing national, cross-state, and regional analyses to support federal and state use cases, as permitted by its Data Privacy and Security Compact (see [Action 5](#)). Reporting may include:

- Topical analyses and benchmarking;
- Public data dashboards, tools, and limited datasets that allow stakeholders to access aggregate national health system information; or
- Ad hoc investigations and information requests to support federal agencies, the Congress, or participating states.

**(5) National HDO—State data exchange:** The National HDO would be responsible for sharing federally administered program data with states in a mutually agreed-to cadence and format. The National HDO would be responsible for serving as the central point of contact for states seeking additional information or technical assistance for federally administered data use.

The National HDO would administer contracting with participating states, as required by the Governance Entity, to set APCD data exchange requirements (e.g., what data participating states will transmit to the National HDO, in what format, at what frequency, and with what quality checks performed).

**(6) Data privacy and security:** The National HDO would be responsible for collecting, managing, analyzing, and exchanging the APCD data in alignment with applicable federal laws and regulations,<sup>428</sup> and the requirements approved by the Governance Entity and its Data Privacy and Security Advisory Committee (see [Action 5](#)). The National HDO would ensure data is stored in a manner that prevents unauthorized access and use. The National HDO would maintain rigorous data security protocols, and require—through its Governance Entity—that participating state APCD agencies meet similar minimum data security protocols for data collection, management, storage, transmission, and use.

**(7) Managing data access, acquisition, and state revenue distribution:** The National HDO would provide users with reasonable access to health system data and for purposes as defined by the Governance Entity. The National HDO would be responsible for managing a centralized, transparent data request process for prospective user access to national APCD data.<sup>429</sup> The National HDO would ensure applicants are aware of data access requirements—including the data security prerequisites—as well as the factors that will be considered for access to be granted. The National HDO Governance Entity may choose to allow tiered data access, with certain users only allowed to access data in the confines of a secure, managed data environment (i.e., “enclave”), wherein use may be monitored and audited, and any data exports would need to be approved. The National HDO would ensure data releases were approved by the Data Privacy and Security Committee (see [Action 5](#)). The National HDO would publicly post abstracts of applications for data access and use; at the conclusion of all projects, full applications would be publicly posted and approved applicants would be required to attest to how data was used and when it was destroyed, and submit documentation of its outputs.

The National HDO would be responsible for implementing data use fees established by the Governance Entity, collecting data access fees, and redistributing revenues back to participating states.<sup>430</sup>

**(8) Coordinating system procurements:** The National HDO may support participating state APCDs in acquiring discounted licensing agreements with software providers (e.g., statistical applications, medical code groupers, quality measure methodologies) for internal analytic use and for use by participating state HDOs.

**(9) Supporting the National HDO Governance Entity:** The National HDO would be responsible for supporting the Governance Entity and the system of governance it required, including:

- Supporting membership appointments and on-boarding;
- Scheduling, convening, and facilitating meetings;
- Developing meeting materials that elevate key decisions and questions for discussion with appropriate context and considerations;
- Managing meetings in coordination with AHRQ staff;
- Ensuring meetings allow for public access and feedback; and
- Other activities as required by the Governance Entity or stipulated in [Action 2](#).

**(10) Operating under public transparency and accountability:** The National HDO would be required to perform these functions in a transparent and accountable manner. The National HDO would be expected to meet federal reporting requirements, potentially including annual reports to federal sponsors, federal legislative authorizing committee(s), and participating states on both the performance of the National HDO and the performance of the U.S. health care system.

### Implementation Costs

The National HDO would require Congressional appropriations to support operations. The LHCC Act budgeted \$20 million for a National HDO's first year of operations, with \$15 million annually thereafter; other reports recommended similar levels.<sup>431</sup> However, to support the scope and collaborative state approach outlined herein, and based on more comprehensive assessment of private sector funding needs for similar endeavors, National HDO annual appropriations of \$50 million may be required to realize the value of the enterprise—a small amount compared with total health care spending and the potential impact the enterprise could have on market transparency, competition, and costs. As one report noted:

\$100 million amounts to less than 0.003% of national health expenditures in 2018—or about \$1 per \$37,000 in health care spending.<sup>432</sup>

The National HDO would be responsible for supporting the Governance Entity ([Action 2](#)) and the Data Privacy and Security Committee ([Action 5](#)); the budgets for these activities are included in this total.

Expenditures required for National HDO establishment would decrease over the first three years and shift to expenditures required for operations, including data collection from participating states and payers/TPAs for non-participating states, and analytics.

AHRQ would be charged with distributing funds, managing National HDO contracting, and general program oversight at an additional staff cost of approximately \$2 million annually.

## Action 2: Establish Federal-State-Consumer Governance Partnership

Soon after the first National HDO is selected and designated by AHRQ, it would be expected to support AHRQ in establishing the joint federal-state-consumer governance partnership—the National HDO Governance Entity—to oversee its ongoing operations.<sup>vii</sup> The Governance Entity would serve as a governing board for the National HDO, overseeing the organization’s activities and ensuring that it is transparent in its operations and accountable for delivering on its scope. The Governance Entity will persist, even if the entity selected to serve as the National HDO changes.<sup>viii</sup>

### National HDO Governance Entity Responsibilities and Functions

The National HDO Governance Entity,<sup>433</sup> directly or in coordination with any advisory groups it may establish, would be responsible for activities including, but not limited to:

- National HDO procurement management, including:
  - Advising AHRQ on the development of future National HDO procurements.
  - Participating in the scoring of a National HDO through the procurement process.
  - Advising on National HDO procurement renewals, contract amendments, and future federal budget requests.
- Setting the National HDO’s strategic, reporting, and data release objectives and priorities, including advising on the development and implementation of a strategic and operating plan for the organization.
- Overseeing the development of and managing changes to:
  - National APCD data standards and a data standards management process.
  - National HDO and participating state minimum APCD data security, privacy, and use standards, based on recommendations from the consumer and privacy advocate community (see [Action 5](#)).
  - National HDO:
    - Data release policies.<sup>434</sup>
    - Policies and procedures to guide its operations, including technical protocols for data requests, data edits, data submission practices, data release, and new state on-boarding.
    - Payer/TPA data request templates and protocols, including minimum lives thresholds, for the direct collection of data from nonparticipating states or non-APCD states.
- Evaluating data release request variances.
- Reviewing and providing expert comment on National HDO draft reporting prior to public release.

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<sup>vii</sup> AHRQ may choose to establish a National HDO Governance Entity in advance of establishing the first National HDO to provide it structured counsel through the procurement process.

<sup>viii</sup> AHRQ will be responsible for managing National HDO vendor transitions and supporting the Governance Entity in instances where the National HDO cannot fulfill this role.

- Soliciting and considering public comment in its deliberations.
- Advising on and approving federal budget requests,<sup>435</sup> including any proposals that implicate funds that states may be asked to contribute or may be eligible to receive related to federal efforts to build state health data capacity.

All decisions, activities, and responsibilities for directing and overseeing the National HDO not specified in the entity's founding charter and subsequent contracting would be the responsibility of AHRQ.

The **National HDO Governance Entity would comprise 21 leaders from the federal government, participating states, consumer privacy representatives, and other health data users.** As similarly proposed in the LHCC Act, the National HDO Governance Entity members would be appointed by the Secretary of HHS in consultation with the Secretary of Labor and the Comptroller General of the United States for staggered three-year terms. Appointees would not have financial conflicts with the National HDO's activities or financial interests in its outputs. Appointees would be expected to have administrative health data expertise to productively advise on key national health data decisions. Appointees would include:

- **Seven** federal agency/department representatives, including representatives from:
  - HHS
    - ASPE
    - CMS
    - AHRQ
    - OCR with expertise in data privacy and security
    - ONC
  - DOL
  - OMB
- **Seven** state APCD agency representatives from participating states<sup>436</sup>
- **Three** consumer advocates, including at least **one** health data privacy and security expert
- **Two** employer and purchaser representatives, including a:
  - Health care purchaser association
  - Large ERISA-preempted self-insured employer
- **Two** health data users and subject matter experts, which may include academic and non-academic researcher(s) with expertise in health economics or health services research, experts in data governance, and others at the discretion of the HHS Secretary

The HHS Secretary would select a non-federal or state agency chair from appointees who would serve for a term of one year. The National HDO Governance Entity may establish advisory committees (e.g., technical advisory committee, reporting advisory committee) that would include representation from payers, as well as other industry participants (e.g., providers, PBMs, pharmaceutical manufacturers, industry associations).



National HDO governance decisions that impact the national APCD data standard or payer data submissions to the National HDO would **not** be considered without implicated payers having the opportunity to respond to the considerations, in writing and in designated public meeting time, with at least 20 business days' notice. The National HDO Governance Entity and its advisory committees would meet in accordance with public meeting laws, posting all non-privileged materials on a public website.

### **Payers and Governance**

Private payers/TPAs play a critical role in America's health care system, managing health services for more than 200 million Americans, and dutifully stewarding and protecting Americans' health care payments and information transactions in alignment with federal and state requirements. There was sharp disagreement from reviewers about whether payers/TPAs should have formal representation in the National HDO Governance Entity. Proponents of formal representation noted that payers/TPAs would offer "real world perspective on the feasibility of reporting data points of interest," flag where new "reporting processes or mechanisms [may be] unreasonably burdensome," and be able to ensure that data of the "highest integrity" is submitted to the National HDO. Opponents of formal representation argued that many payers/TPAs have been persistent state APCD detractors and critics and—at times—difficult participants in submitting accurate data to APCDs; they shared that providing payers/TPA a role in National HDO governance would present a conflict of interest.

This paper recommends establishing the National HDO Governance Entity without health care industry participation to avoid any real or perceived conflicts of interest as the National HDO seeks to add transparency and accountability to our nation's health care system for the American public. However, it also proposes a requirement that the National HDO and its Governance Entity seek payer/TPA feedback after decisions that implicate payer/TPA reporting requirements. While this author has never experienced payers/TPAs serving as anything other than good-faith APCD data submission partners (though at times, overburdened partners), the author has experienced states requiring data from payers that are simply not available in their data systems or would require significant payer/TPA effort to produce little value-add. Productive partnerships require good-faith efforts and consideration of both actors. The requirement for payer/TPA consultation will hopefully provide both incentive and public recourse to national APCD standards changes that would prove unduly burdensome for payers/TPAs or unproductive for the National HDO.

### **Implementation Costs**

The National HDO/AHRQ would require funding to establish a joint-governance body, with expenditures higher in early years as the governance body is established. Establishment and support for the National HDO Governance Entity could cost \$5 million in the first implementation year as initial charters and bylaws are developed, declining to an ongoing expenditure of \$3 million thereafter.<sup>ix</sup>

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<sup>ix</sup> Included in National HDO budget total.

## Action 3: Resolve Self-Insured Data Reporting Barriers

Concurrent to developing a national APCD data standard, the federal government should confirm its authority to require the collection of self-insured data covered under ERISA (see Section IV.2.1). While DOL and HHS have existing—and previously exercised—authorities under ERISA and the ACA, respectively, to collect the type of information in APCD files from self-insured employers and their TPAs by a common standard, a court’s ruling would likely be (solicited and) necessary to settle public discourse about whether it has the authority to collect the depth of information in APCD files (i.e., person-level claims data) and whether it could delegate that authority (e.g., to states, to a National HDO).<sup>437</sup> Congressional clarification of the issue would also likely and unequivocally resolve the issue, potentially only requiring clerical amendments to related laws.

### The Question of Executive Authority

As discussed extensively in Sections III.E and IV.2.1, while health data stakeholders broadly agree that the federal government has the present or potential authority to collect ERISA-preempted self-insured data using a designated uniform national data collection standard (and largely, the benefit of its doing so), they disagree on whether that authority currently exists or requires further Congressional action. Several of these positions are summarized for convenience, below.

The first suggestion of federal authority to collect data for plans covered by ERISA was made in *Gobeille*. The ruling noted that the “Secretary of Labor has authority to establish additional reporting and disclosure requirements for ERISA plans. ERISA permits the Secretary to use the data disclosed by plans ‘for statistical and research purposes, and [to] compile and publish such studies, analyses, reporting and surveys based thereon as he may deem appropriate... [and] may be authorized to require ERISA plans to report data similar to that which Vermont seeks,” though stated that was not the question at issue in the ruling.<sup>438</sup> Justice Breyer expanded on the suggestion in his concurrence, “Pre-emption does not necessarily prevent Vermont or other States from obtaining the self-insured, ERISA-based health-plan information that they need. States wishing to obtain information can ask the Federal Government for appropriate approval... I see no reason why the Secretary of Labor could not develop reporting requirements that satisfy the States’ needs, including some State-specific requirements, as appropriate. Nor do I see why the Department could not delegate to a particular State the authority to obtain data related to that State, while also providing the data to the Federal Secretary for use by other States or at the federal level.”

A 2019 paper by legal scholars at the University of California, Hastings (UC Hastings), agreed: “To require ERISA plans to report health care and drug utilization and price information [for an APCD], the [DOL] could independently create federal regulations governing health care transparency, or it could work with state or private entities to coordinate those efforts. To do so, the [DOL] could use its existing authority under the [ACA] and ERISA to require self-funded health plans and their administrators to report a standardized set of data about health care claims and drug pricing to the [DOL]. The statutory authority for the [DOL] to require ERISA plans to submit health care claims data derives from Public Health Service Act (PHSA) § 2715A, which authorizes collection of data on health care costs and payments, and PHSA § 2717, which authorizes collection of data on health care quality. Both provisions were among those health insurance reforms created by the ACA and applied to group health plans by ERISA § 715. In addition, the [DOL] has authority to collect data under the provisions of ERISA §§ 104 and 505, which authorize [it] to promulgate regulations and require any information or data from plans as necessary to carry out the purposes of the statute.”<sup>439</sup>

In response to the national APCD provision in the LHCC Act, the American Benefit Council—a national nonprofit organization dedicated to protecting employer-sponsored benefit plans, which “represents more major employers ... than any other association that exclusively advocates on the full range of employee benefit issues”<sup>440</sup>—expressed support for “the establishment of an all-payer claims database at the federal level.”<sup>441</sup> It noted though that the Act’s “provision [allowing its creation] appears largely redundant to the current requirements imposed on group health plans and health insurance issuers through Section 2715A of the [Public Health Services Act (PHSA)] and, by incorporation, Section 715 of ERISA” (as similarly stated by UC Hastings).

ERIC, a strong and effective protector of ERISA, has also supported “the creation of a national APCD,” as a “federal solution” that would “fill data gaps for states, empower plan sponsors with data, and ensure that ERISA plans are not subject to state efforts to implement claims data reporting regimes.”<sup>442</sup> As shared in its public comment to Form 5500 Schedule J reforms, however, its position appears to be that the authority for such collection lay with Congress, not with the DOL under its existing regulatory authority: “If there is to be a federally-run all-payers health claims database, that database will require specific legislative authorization, which will necessarily include details relating to what must be reported, to whom, by whom, when, and in what format. All of these determinations require congressional action and, as such, are at this time outside of the authority of the [DOL] to make.”<sup>443</sup>

It is unclear whether ERIC’s position has changed on the issue, particularly since Congress passed the CAA in 2020, which introduced broad new health care spending data reporting requirements on self-insured health plans to allow policymakers “data to make informed decisions” in support of market competition.<sup>444</sup> “RxDC” reporting requirements are being exercised for the first time by DOL and HHS in December.

## Potential Agency and Congressional Actions

The DOL and HHS, in coordination with the National HDO Governance Entity and other stakeholders, should take the following actions to resolve the ERISA-preempted self-insured reporting barrier:

**(1) Create a National APCD Data Standard:** As described in [Action 1](#), the National HDO Governance Entity—which includes self-insured employer and purchaser representation (see [Action 2](#))—and its APCD SAG—which includes payers/TPAs—should develop a national APCD data standard that would allow for the uniform collection of all state APCD data, not just that of the self-insured, reducing the payer/TPA reporting burden and eliminating ungoverned state-by-state APCD data reporting variation.

**(2) Resolve DOL/HHS Data Collection Authority:** As described in Section [IV.2.1](#), the DOL and HHS should confirm their authorities to promulgate a national standard for the collection of ERISA-governed self-insured data and require its reporting to state or national APCDs. If DOL/HHS authorities are determined to be unclear, Executive agency leaders should work with congressional leaders to reaffirm their authority in limited legislation that offers clarifying amendments to allow the federal government to collect information about an industry responsible for providing health care coverage for nearly a third of Americans.\*

**(3) Establish Reporting Incentives:** Even if data collection authority is reaffirmed, the DOL, HHS/AHRQ, and the National HDO should explore opportunities with ERIC, the American Benefits Council, and other stakeholders to sunset existing self-insured employer reporting requirements with the introduction of APCD data collection. For example, the DOL may determine that parts of the Form 5500 or RxDC reports can be substantively generated through APCD file analysis and can be retired, relieving employers of reporting burden or payer/TPA reporting costs.<sup>445</sup> The DOL/HHS may also prohibit payers/TPAs from charging fees to self-insured employers for the submission of their data to APCDs.<sup>446</sup>

## Implementation Costs

To support these efforts, the DOL may require funding of up to \$5 million in its first years to cover staffing costs, including internal and external counsel. Costs would likely decrease significantly after the legal issue is resolved, potentially as soon as the third year of program implementation, falling to a recurring \$1 million budget line item annually.

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\* While briefly stated here, it is not without appreciation for the significant work and negotiation this step requires, which could take several years to fully resolve.

## Action 4: Establish Federal Source of State Health Data Organization Funding

Federal agencies should work with Congress, as needed, to authorize and appropriate funding to support ongoing state health data use for market transparency and oversight, and state implementation of the new national APCD model, investing in and building from existing state APCD infrastructure.

### New Federal Funding Pathways

Federal health data funding may include:

- One-time state APCD agency national APCD implementation grants;
- Ongoing state APCD agency and HDO system maintenance and programming funds; and
- One-time state health data innovation grants.

#### (1) AHRQ State National APCD Implementation Grants

The federal government may establish capacity-building grants for states seeking to participate in the federally facilitated APCD model. Federal funding should extend beyond the originally proposed—though not appropriated—CAA state APCD capacity-building grants (\$2.5 million over three years) in amount and duration to meet the anticipated need. Funding of up to \$4 million per state HDO/APCD Agency is recommended over a five-year period.<sup>447</sup> States with existing APCDs may use funds to implement the process and system changes required to align with new national APCD data and data privacy/security standards. States without existing APCDs may use funds to establish APCD capacity within an HDO in alignment with national standards. The federal government may allow states to pool funds for the purpose of establishing regional health data collaboratives (e.g., establishing regional APCDs within regional Health Data Utilities (HDUs) to support states where data collection capacity does not presently exist).

AHRQ would be the administering agency for these grants, though may wish to divest grant administration responsibilities to the National HDO.

#### (2) CMS Expanded Matching Funds

As discussed in Sections III.D, IV.1.1, and IV.4.1, CMS, in coordination with OMB, may update Medicaid cost allocation guidance and Medicaid MES funding guidance to clarify the extent of state APCD expenditure eligibility<sup>448</sup> and potentially expand existing federal Medicaid administrative cost allocation guidelines to cover a greater share and match of APCD operating expenses, to the extent the APCD will be used for Medicaid-focused market analyses and to address concerns disproportionately experienced by the Medicaid population.<sup>449,450</sup>

CMS may require state HDOs that steward APCDs and leverage expanded matching funds to report annually on their efforts to meet these ends.

### (3) CMMI State Health Data Innovation Grants

CMMI may establish a health data innovation grants program for state HDOs that steward APCDs (which may include HDUs), similar to earlier SIM grants, that would provide states with funding to pursue activities of potentially national interest. Potential examples of such endeavors may include:

- Piloting state APCD and HIE data linkages to develop member-level health indicator flags to support plan- and provider-level care management;
- Testing new APCD data collection fields or transmission methods (e.g., FHIR API transmission);
- Aligning and testing common methods for the collection of non-claims-based payment data for future APCD collection;
- Supporting payers and providers with the development of median market rates (i.e., supporting No Surprises Act payment negotiations);
- Piloting new program, policy, and regulatory use cases; and
- Bridging various health and human service data assets with state APCDs to generate a greater understanding of whole-person health and public health needs.

Innovation grant values may vary depending on the proposed project and applicant need. Grant recipients would be expected to publicly report on project milestones, outputs, and lessons learned to inform potential cross-state scalability.

CMMI would be the administering entity for these grants.

### Implementation Costs

Total state distributions to support HDO capacity building and APCD data harmonization and use could total \$50 million to \$75 million annually, depending on the number of participating states, and distributed as follows:

- **AHRO State National APCD Implementation Grants** could total \$120 million over five years, assuming 30 states draw down the allowable \$4 million in funds.
- **CMS Expanded Matching Funds** could total between \$30 million and \$45 million annually assuming 30 states qualify for an additional 50% match for a newly eligible \$3 million of expenditures per state.
- **CMMI State Health Data Innovation Grants** could be capped at \$5 million per year, with distribution priorities changing annually to reflect national health data needs.

Distributions are likely to be higher in the early years.

## Action 5: Establish National Compact on APCD Data Privacy and Security

Americans are concerned about how their health data is being accessed and used. While state APCDs invest heavily in data privacy and security, they are not governed by consistent data privacy and security standards (see Section III.B). The establishment of a National HDO and APCD **system** that invests in and builds from existing state infrastructure, presents an opportunity to **develop a national trust framework for the establishment of uniform and baseline APCD data privacy and security standards.**<sup>451</sup>

Shortly after its establishment, the National HDO may establish<sup>452</sup> a Data Privacy and Security Advisory Committee to advise on the development of baseline data privacy, security, and release standards for the National HDO's and participating states' APCDs, creating minimum national health data privacy and security standards for APCDs nationally.

### National HDO Data Privacy and Security Advisory Committee

In close coordination with federal and National HDO legal counsel, the Committee may be asked to:

- Advise the National HDO on the:
  - Federal laws and regulations with which it must comply as it plans to collect, transmit, store, manage, and release health administrative data; and
  - Federal and state laws and regulations with which participating states will need to comply as they plan to collect, transmit, store, manage, and release health administrative data in accordance with the National HDO partnership agreement.<sup>453</sup>
- Recommend to the National HDO minimum national data security, privacy, and release standards that would ensure individual health data is protected in-line with federal requirements. This may include, but is not limited to, requiring the National HDO to:
  - Handle data in accordance with HIPAA and, if applicable, the Privacy Act;
  - Institute strong deidentification provisions;
  - Implement security credentials such as HITRUST; or
  - Institute release restrictions for particular data types (e.g., behavioral health, substance use, sexual orientation, gender identity, reproductive health data, HIV data) and protocols that maximize data release transparency and oversight.
- Recommend to the National HDO minimum requirements for:
  - The organizations or individuals that may access National HDO/state APCD requirements;
  - The purpose(s) for which organizations or individuals may access National HDO/state APCD data; and
  - The level of data granularity organizations/individuals may be able to access.

- Advise on the development of the National HDO data request and release process, including the application and criteria for release.
- Review and approve National HDO data releases.
- Ensure the National HDO and participating states are managing data privacy, security, and release practices in a transparent manner and in accordance with established policies and procedures.

The Committee would comprise leaders from the federal government, participating states, consumer advocates, and private experts. Appointees would be made by AHRQ, in coordination with the National HDO Governance Entity. Appointees would be expected to have administrative health data security and privacy expertise to productively advise on key national health data decisions.

### **Implementation Costs**

AHRQ and the National HDO would require funding to establish and provide the Committee with the appropriate level of support. Funding needs may total \$5 million in the first year as an initial data privacy and security framework is established, and \$3 million thereafter, as AHRQ/National HDO consults internal and external counsel to keep the Compact current and ensure compliance.<sup>xi</sup>

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<sup>xi</sup> Included in National HDO budget total.



## VII. Conclusion

Through implementing the recommendations outlined in Section VI, the federal government, in partnership with states, payers, and consumer and privacy advocates, would strengthen our nation's state-based APCD operating model, address many of its present limitations, and unlock its full market-changing potential for the public good. Taking these actions would:

- Increase national administrative health data collection and use by creating a central, protected administrative health data repository.
- Stem growing state health data inequities and support state APCD agency sustainability by creating new funding sources for APCD establishment, maintenance, and innovative use.
- Improve state APCD data completeness by creating a pathway for states to collect or receive data for residents that are self-insured or covered by a federally administered health program.
- Reduce payer reporting burden and enhance APCD data utility by standardizing state APCD data.
- Preserve state data stewardship and provide states a voice equal to that of federal officials in how the National HDO may be governed.
- Align state data privacy and security standards to reduce state by state variation in how state APCD data is collected, managed, and exchanged.

While this paper covers significant ground in outlining the issues these recommendations set out to address, inevitably there will be additional terrain to cover. Federal, state, and public changemakers seeking to operationalize these recommendations will need to further unpack many of the issues and solution strategies highlighted herein, including, most notably, untangling the federal legal and regulatory complexities of making the collection of ERISA-preempted self-insured data possible, and developing a rigorous data privacy trust framework that will protect our national health information from use in unintended ways. But for all that is left to do, we must remember that it is important, foundational, and necessary work that must be advanced for us to be responsible stewards of the public interest, equipped with the information we need to resolve the often-complex issues endemic to our complex system of health. It is information worth fighting for.

## Appendix: Interviewees, Reviewers, and Contributors

The following individuals provided invaluable input through the paper development process, from landscape confirmation to model and proposal development and testing. We particularly want to thank the: representatives from the Agency for Healthcare Research and Quality (AHRQ) and the Office of the Assistant Secretary for Planning and Evaluation (ASPE) for taking the time to engage around the models and proposals; Jo Porter, Co-chair of the All Payer Claims Database (APCD) Council and a true and generous expert on state APCDs; Lucia Savage, for her brilliant comments; Jessica Kahn, for her practical insights on how federal and state governments may make such proposals *work*; and Claudia Williams, for reviewing this paper and sharing such thoughtful feedback while on a well-earned sabbatical. For all the expert feedback received, the views expressed in this paper are solely those of the author and do not necessarily reflect the views of the paper's reviewers.

### Federal Leadership

We would like to thank representatives from the following Health and Human Service agencies and offices for their substantive and invaluable input through the development of this paper, including:

- Agency for Healthcare Research and Quality (AHRQ)
- Centers for Medicare and Medicaid Services, Center for Medicaid and CHIP Services (CMCS) and Office of Enterprise Data and Analytics (OEDA)
- Office of the Assistant Secretary for Planning and Evaluation (ASPE)

### State Leadership

Many thanks to the state health data leaders who shared their input through the development of this paper, including:

- Ray Campbell, Executive Director, Massachusetts Center for Health Information and Analysis
- Karynlee Harrington, Executive Director, Maine Health Data Organization<sup>454</sup>
- Kathy Hines, Senior Director of Partner Operations and Data Compliance, Massachusetts Center for Health Information and Analysis<sup>455</sup>
- Starla Ledbetter, Chief Data Officer, California Department of Health Care Access and Information<sup>456</sup>
- Carl Letamendi, Bureau Director of Center for Health and Data Informatics, Utah Office of Health Care Statistics<sup>457</sup>
- Jo Porter, Director, Institute for Health Policy and Practice, University of New Hampshire<sup>458</sup>
- Kyle Russell, CEO, Virginia Health Information<sup>459</sup>
- Dr. Joseph Thompson, CEO, Arkansas Center for Health Improvement<sup>460</sup>
- Norm Thurston, Executive Director, National Association of Health Data Organizations
- Vicki Veltri, Executive Director,<sup>461</sup> Connecticut Office of Health Strategy

## Payer Leadership

Sincere thanks to the payer representatives who were willing to review and provide comments on the paper, including Bernie Inskeep, APCD Program Director at UnitedHealthcare, and the four other representatives from national insurance, insurance association, and actuarial organizations.<sup>462</sup>

## National Health Data Thought Leaders

- Lisa Bari, CEO, Civitas Networks for Health
- Dr. Lynn Blewett, Director, State Health Access Data Assistance Center<sup>463</sup>
- Rachel Block, Program Officer, Milbank Memorial Fund
- Niall Brennan, Chief Analytics and Privacy Officer, Clarify Health
- Dr. Michael Chernen, Professor and Director, Healthcare Markets and Regulation Lab, Harvard Medical School
- Dr. Margo Edmunds, Vice President, Evidence Generation and Translation, AcademyHealth
- Jeanette Contreras, Project Director, Health Equity Campaigns, UnidosUS
- Dr. Matthew Fiedler, Senior Fellow, USC-Brookings Schaeffer Initiative for Health Policy
- Helen Figge, Chief Strategy Officer, MedicaSoft<sup>464</sup>
- John Freedman, President, Freedman HealthCare
- Jim Harrison, President/CEO, Onpoint Health Data
- Dr. Erin Holve, Chief Research Infrastructure Officer, Patient-Centered Outcomes Research Institute
- Emma Hoo, Director, Purchaser Business Group on Health
- Jessica Kahn, Partner, McKinsey
- Jeff Leintz, Vice President, Advance Data Solutions Center, NORC at the University of Chicago<sup>465</sup>
- Kevin Lucia, JD, Research Professor, Co-founder, Co-director, Center on Health Insurance Reforms (CHIR), Georgetown University
- Douglas McCarthy, President, Issues Research, Inc.<sup>466</sup>
- Deven McGraw, JD, Lead, Data Stewardship & Data Sharing, Invitae
- Maureen Mustard, Chair,<sup>467</sup> U.S. DOL State All Payer Claims Database Advisory Committee
- Lauren Riplinger, JD, Vice President, Policy & Government Affairs, American Information Management Association
- Lucia Savage, JD, Chief Privacy and Regulatory Officer, Omada Health
- Samantha Scotti, Project Manager, Health Program, National Conference of State Legislatures
- JoAnn Volk, Research Professor, Co-founder, Co-director, Center on Health Insurance Reforms, Georgetown University
- Claudia Williams, CEO,<sup>468</sup> Manifest MedEx

<sup>1</sup> “How does health spending in the U.S. compare to other countries?” Peterson-Kaiser Family Foundation (KFF) Health System Tracker, January 21, 2022. Accessed July 25, 2022. Available [here](#).

<sup>2</sup> “How does U.S. life expectancy compare to other countries?” Peterson-KFF Health System Tracker, September 28, 2021. Accessed July 25, 2022. Available [here](#).

<sup>3</sup> “National Health Expenditure Data,” Centers for Medicare & Medicaid Services (CMS). Accessed May 25, 2022. Available [here](#).

<sup>4</sup> “Americans’ Challenges with Health Care Costs,” KFF, July 14, 2022. Accessed July 27, 2022. Available [here](#).

<sup>5</sup> “Achieving Racial and Ethnic Equity in U.S. Health Care,” The Commonwealth Fund, November 18, 2021. Accessed July 27, 2022. Available [here](#).

<sup>6</sup> “COVID-19 Cases and Deaths by Race/Ethnicity: Current Data and Changes Over Time,” KFF, February 22, 2022. Accessed July 27, 2022. Available [here](#).

<sup>7</sup> “Update: How Many Americans Have Lost Jobs with Employer Health Coverage During the Pandemic?” The Commonwealth Fund, January 11, 2021. Accessed July 27, 2022. Available [here](#).

<sup>8</sup> “National Health Expenditure Data,” CMS. Accessed May 25, 2022. Available [here](#).

<sup>9</sup> “How does health spending in the U.S. compare to other countries?” Peterson-KFF Health System Tracker, January 21, 2022. Accessed July 27, 2022. Available [here](#).

<sup>10</sup> For example, see Colorado’s Center for Improving Value in Health Care’s (CIVHC) state cost analysis: “Total Cost of Care Multi-State Analysis,” CIVHC, February 2018. Available [here](#). Also see: “Healthcare Procedure Cost Drivers,” Maine Health Data Organization. Accessed May 25, 2022. Available [here](#).

<sup>11</sup> For example: “HPC DataPoints, Issue 22, Growth in Out-of-Pocket Spending for Pregnancy, Delivery, and Postpartum Care in Massachusetts,” Health Policy Commission (HPC), March 29, 2022. Accessed August 15, 2022. Available [here](#).

<sup>12</sup> For more examples of potential Medicaid APCD use cases, see: “Recommendation Report for Expanded Access to the Minnesota All-Payer Claims Database: Initial Findings – Appendix D,” Minnesota Department of Health (MDH), February 2022. Accessed May 25, 2022. Available [here](#).

<sup>13</sup> For example, the Utah Department of Health’s Office of Health Care Statistics (OHCS) used the Utah APCD to assess provider payment variation for colonoscopies, a commonly considered “shoppable service.” It found that payments around its median price ranged by 400%, “demonstrat[ing] that selecting a low-cost provider may be possible” with minimal research. “Exploring the Cost of Colonoscopy in Utah July 2019 through June 2020,” Utah Department of Health, OHCS, March 23, 2021. Accessed May 25, 2022. Available [here](#). Virginia Health Information (VHI), which stewards the Virginia APCD under the authority of the Virginia Department of Health, used its APCD to quantify the volume and costs of preventable ED visits in the state, finding that “about 10% of the 1.1 million ED visits in 2020 may have been potentially avoided and treated with lower cost care in a [primary care practitioner’s] office” while generating health system savings of nearly \$67 million. “Potentially Avoidable ED Visits in 2020,” VHI, May 2, 2022. Accessed May 25, 2022. Available [here](#).

<sup>14</sup> Massachusetts’ APCD was used as the backbone for the state’s opioid use disorder analysis in 2017: “An Assessment of Fatal and Nonfatal Opioid Overdoses in Massachusetts (2011 – 2015),” Commonwealth of Massachusetts, August 2017. Accessed May 25, 2022. Available [here](#).

<sup>15</sup> For example, Massachusetts’ CHIA supports payer/provider price transparency initiatives through its Compare Treatment Costs tool and broader bulk releases of procedure price data. For more information, see: “CompareCare,” Commonwealth of Massachusetts. Accessed May 25, 2022. Available [here](#). Also see: “Bulk Release of Procedure Price Data,” CHIA. Accessed May 25, 2022. Available [here](#). “CompareMaine,” Maine HDO. Accessed May 25, 2022. Available [here](#).

<sup>16</sup> “National Health Expenditure Data,” CMS. Accessed May 25, 2022. Available [here](#).

<sup>17</sup> “How does U.S. life expectancy compare to other countries?” Peterson-KFF Health System Tracker. September 28, 2021. Accessed May 25, 2022. Available [here](#).

<sup>18</sup> This paper focuses on health system administrative data, claims and encounters, and records of services rendered to patients by providers and which typically include additional information on patient diagnoses and payment amounts between payers and providers.

<sup>19</sup> States had previously exercised this authority to a greater extent, regularly collecting detailed hospital data to support rate regulation. Maryland continues to maintain a rate-setting board.

<sup>20</sup> For more information on state cost growth benchmarking programs, see the “The Manatt State Cost Containment Update,” Manatt Health. Accessed August 25, 2022. Available [here](#).

<sup>21</sup> Pricing information may not be reflective of the amount paid to a payer/provider if payment is made under alternative payment arrangement, a major deficiency of any claims-based data resource.

<sup>22</sup> Race and ethnicity data collection remains uneven among state APCDs and payer types.

<sup>23</sup> Premium data collection remains rare across states.

<sup>24</sup> Some states may collect a limited amount of provider demographic and health system affiliation data.

<sup>25</sup> “HIPAA Turns 10: Analyzing the Past, Present, and Future Impact,” Journal of AHIMA. April 6, 2013. Accessed November 15, 2022. Available [here](#). Appreciation for reviewer Lucia Savage for directing attention to this article.

<sup>26</sup> West Virginia enacted a new statute and a new rule in 2022. For more information, see: “All-Payer Claims Database,” West Virginia Department of Health & Human Resources. Accessed May 25, 2022. Available [here](#).

<sup>27</sup> “All Payer Claims Database Procurement Plan,” State of Nevada Department of Health and Human Services. February 2, 2022. Accessed November 15, 2022. Available [here](#).

<sup>28</sup> Modeled using data available from the: “APCD Interactive State Report Map,” APCD Council, a program of the National Association of Health Data Organizations (NAHDO) and the University of New Hampshire. Accessed May 25, 2022. Available [here](#).

<sup>29</sup> In partnership with the NH Department of Health and Human Services (NH DHHS).

<sup>30</sup> The Health Insurance Rate Review Division (HIRRD) of the Arkansas Insurance Department was awarded a Cycle III grant from CMS to establish an APCD. HIRRD selected the Arkansas Center for Health Improvement (ACHI) to establish and manage the state’s APCD.

<sup>31</sup> Supported by government but privately managed.

<sup>32</sup> “Interactive State Report Map,” APCD Council, a Program of NAHDO and the University of New Hampshire. Accessed May 25, 2022. Available [here](#).

<sup>33</sup> “White Paper: Overview of All-Payer Claims Databases in the United States - A Report for Employers and Other Health Care Purchasers,” Employers’ Forum of Indiana. February 9, 2020. Accessed July 27, 2022. Available [here](#).

<sup>34</sup> “The Basics of All-Payer Claims Databases: A Primer for States,” APCD Council. January 2014. Accessed July 25, 2022. Available [here](#). “The ABCs of APCDs,” APCD Council/CHCF. November 8, 2018. Accessed July 25, 2022. Available [here](#).

<sup>35</sup> “State All-Payer Claims Databases: Tools for Improving Health Care Value, Parts 1 and 2,” The Commonwealth Fund. December 2020. Accessed July 27, 2022. Available [here](#) and [here](#), respectively.

<sup>36</sup> “Health Care Payments Data Program Report to the Legislature,” California Office of Statewide Health Planning and Development/Freedman HealthCare. March 9, 2020. Accessed July 27, 2022. Available [here](#).

<sup>37</sup> “All-Payer Claims Database Development Manual,” West Health/APCD Council. March 4, 2015. Accessed July 24, 2022. Available [here](#). “Model All-Payer Claims Database (APCD) Legislation,” APCD Council. May 2015. Accessed July 27, 2022. Available [here](#).

<sup>38</sup> Payers with a state employee health benefit plan are contractually required to submit their data to the WHIO.

<sup>39</sup> “A County Level Comparison of Quality and Effective Use of Resources for Primary Care Practices in Wisconsin,” WHIO. June 13, 2018. Accessed May 25, 2022. Available [here](#). “COVID-19 in Wisconsin,” WHIO. Accessed May 25, 2022. Available [here](#).

- <sup>40</sup> “Combining Clinical and Claims Data Is the Future of HIE,” Manifest MedEx. Accessed July 27, 2022. Available [here](#).
- <sup>41</sup> “2019 Survey on HIE Technology Priorities: The Status of Health Information Exchange in 2019,” eHealth Initiative Foundation. 2019. Accessed July 27, 2022. Available [here](#).
- <sup>42</sup> “eHI Survey: HIEs Seeing More Demand for Merged Clinical, Claims Data,” Healthcare Innovation. May 17, 2019. Accessed July 27, 2022. Available [here](#).
- <sup>43</sup> “Expanding Health Data Utility Models and Advancing Standards for Public Health,” HIMSS Interoperability and HIE Community. February 2, 2022. Accessed July 27, 2022. Available [here](#). “Health Data Utilities: Enhancing and Exchanging Health Data for Health Equity and Health Improvement,” Civitas Networks for Health. April 2, 2022. Accessed July 2, 2022. Available [here](#).
- <sup>44</sup> Note: Nonprofits HCCI and FAIR Health have made significant data assets available for researcher and public use, and regularly seek to work with non-commercial users to address price concerns.
- <sup>45</sup> “Real-world evidence,” Merative. Accessed July 27, 2022. Available [here](#).
- <sup>46</sup> “How a decades-old database became a hugely profitable dossier on the health of 270 million Americans,” STAT. February 1, 2022. Accessed May 25, 2022. Available [here](#).
- <sup>47</sup> “Real-world evidence must not become evidence for abortion-related prosecution,” STAT News. July 8, 2022. Accessed July 27, 2022. Available [here](#).
- <sup>48</sup> “H.R. 8152 – American Data Privacy and Protection Act,” U.S. Congress. July 20, 2022. Accessed August 25, 2022. Available [here](#).
- <sup>49</sup> This exhibit does not account for lives captured by state MPCDs.
- <sup>50</sup> Manatt analysis of state APCD populations; some states report higher rates.
- <sup>51</sup> Half of Americans are covered by employer-sponsored insurance (ESI), and nearly two-thirds (64%) of those are covered through self-insured plans. For more information, see “Health Insurance Coverage of the Total Population,” Kaiser Family Foundation. 2019. Accessed July 25, 2022. Available [here](#). “Employer Health Benefits: 2021 Annual Survey,” Kaiser Family Foundation. 2021. Accessed July 25, 2022. Available [here](#).
- <sup>52</sup> “*Gobeille, Chair of the Vermont Green Mountain Care Board v. Liberty Mutual Insurance Co.*,” Supreme Court. October Term, 2015. March 1, 2016. Accessed July 25, 2022. Available [here](#).
- <sup>53</sup> “ERISA Preemption Primer,” National Academy for State Health Policy (NASHP). Accessed July 27, 2022. Available [here](#).
- <sup>54</sup> “Key State Health Care Databases for Improving Health Care Delivery,” NAHDO. February 2011. Accessed August 29, 2022. Available [here](#).
- <sup>55</sup> For example: “Total Cost of Care Multi-State Analysis,” CIVHC. February 2018. Accessed August 15, 2022. Available [here](#). “Healthcare Procedure Cost Drivers,” Maine Health Data Organization. Accessed May 25, 2022. Available [here](#).
- <sup>56</sup> For example: “HPC DataPoints, Issue 22, Growth in Out-of-Pocket Spending for Pregnancy, Delivery, and Postpartum Care in Massachusetts,” HPC. March 29, 2022. Accessed August 15, 2022. Available [here](#).
- <sup>57</sup> For Medicaid APCD use cases, see “Recommendation Report for Expanded Access to the Minnesota All Payer Claims Database: Initial Findings – Appendix D,” MDH. February 2022. Accessed August 15, 2022. Available [here](#).
- <sup>58</sup> For example: The Utah APCD was used to assess provider payment variation for colonoscopies, a common “shoppable service.” It found that payments ranged by 400%, “demonstrat[ing] that selecting a low-cost provider may be possible” with minimal research. “Exploring the Cost of Colonoscopy in Utah July 2019 through June 2020,” Utah Department of Health, OHCS. March 23, 2021. Accessed August 15, 2022. Available [here](#). The Virginia APCD was used to quantify the volume and costs of preventable ED visits, finding that “about 10% of the 1.1 million ED visits in 2020 may have been potentially avoided and treated with lower cost care in a [primary care practitioner’s] office,” while generating health system savings of nearly \$67 million. “Potentially Avoidable ED Visits in 2020,” VHI. May 2, 2022. Accessed August 15, 2022. Available [here](#).

- <sup>59</sup> For example, Massachusetts' APCD was used as the backbone for the state's opioid use disorder analysis in 2017: "An Assessment of Fatal and Nonfatal Opioid Overdoses in Massachusetts (2011 – 2015)," Commonwealth of Massachusetts. August 2017. Accessed August 15, 2022. Available [here](#).
- <sup>60</sup> For example: "CompareCare," Commonwealth of Massachusetts. Accessed May 25, 2022. Available [here](#). "Bulk Release of Procedure Price Data," CHIA. Accessed May 25, 2022. Available [here](#). "CompareMaine," Maine Health Data Organization. Accessed May 25, 2022. Available [here](#).
- <sup>61</sup> The 2020 No Surprises Act created an explicit APCD use case for payers and providers. The act defined the Qualifying Payment Amount (QPA), which patients are required to pay for surprise out-of-network bills when state law does not set an amount, as the median of plan or insurer's in-network contracted rates for a given item or service in a given geographic region. CMS noted that APCDs may be used to calculate QPAs. "Qualifying Payment Amount Methodology," CMS. December 2021. Accessed July 27, 2022. Available [here](#).
- <sup>62</sup> For example, the MHI uses its MPCD to generate basic population health statistics for public use: "St. Louis MSA Health Stats: A Community Scorecard for Commercial Populations," MHI. August 2019. Accessed July 27, 2022. Available [here](#).
- <sup>63</sup> For example, Massachusetts uses its APCD to estimate the potential fiscal impact of any new proposed Medicaid (MassHealth) benefit. "Mandated Benefit Review of Senate Bill 597 Submitted to the 191st General Court: An Act Providing Coverage for Hearing Aids," CHIA/BerryDunn. January 2021. Accessed August 29, 2022. Available [here](#).
- <sup>64</sup> "Studying Medical Marijuana: Research Project by ACHI, UAMS To Be First of Its Kind," Arkansas Center for Health Improvement (ACHI). December 1, 2021. Accessed May 25, 2022. Available [here](#).
- <sup>65</sup> "Affordability Dashboard," Center for Improving Value in Health Care (CIVHC). Accessed May 25, 2022. Available [here](#).
- <sup>66</sup> "Connecticut State Innovation Model: Final Evaluation Report," UConn Health/Yale School of Public Health. 2020. Accessed July 27, 2022. Available [here](#).
- <sup>67</sup> "An Investigation into Opioid Prescriptions and ED Events in Delaware 2016-2020," DHIN. February 2022. Accessed July 27, 2022. Available [here](#).
- <sup>68</sup> "Prescription Drug Costs and Utilization in Maine at Retail and Mail Order Pharmacies," Maine Health Data Organization. July 6, 2022. Accessed May 25, 2022. Available [here](#).
- <sup>69</sup> "Enrollment in Health Insurance," Massachusetts Center for Health Information and Analysis (CHIA). Accessed May 25, 2022. Available [here](#).
- <sup>70</sup> "Publications Using the MN APCD," Minnesota Department of Health (MDH). Accessed May 25, 2022. Available [here](#).
- <sup>71</sup> "Network Adequacy Standards and Enforcement," Kaiser Family Foundation. February 4, 2022. Accessed May 25, 2022. Available [here](#).
- <sup>72</sup> "2020 Primary Care Spending in Oregon Report Executive Summary," OHA. June 2022. Accessed May 25, 2022. Available [here](#).
- <sup>73</sup> "HealthFacts RI Public Reports: Follow-up Rates after ED Visits for Mental Illness" and "Follow-up Rates after ED Visit for Substance Abuse," Rhode Island Department of Health. Accessed May 25, 2022. Available [here](#).
- <sup>74</sup> "Exploring the Cost of Colonoscopy in Utah July 2019 through June 2020," Utah Department of Health, Office of Health Care Statistics (OHCS). March 23, 2021. Accessed May 25, 2022. Available [here](#).
- <sup>75</sup> "Balance Billing: Commercially Reasonable Payments Dataset," Virginia State Corporation Commission. Accessed July 27, 2022. Available [here](#).
- <sup>76</sup> "APAC Data Now Linked to Oregon Death Record Data," Oregon Health Authority. August 18, 2020. Accessed July 27, 2022. Available [here](#).
- <sup>77</sup> "An Assessment of Fatal and Nonfatal Opioid Overdoses in Massachusetts (2011 – 2015)," Commonwealth of Massachusetts. August 2017. Accessed July 27, 2022. Available [here](#).

<sup>78</sup> “GMCB Analytic and Data Team Update,” Vermont Green Mountain Care Board. January 27, 2021. Accessed July 27, 2022. Available [here](#).

<sup>79</sup> “Healthcare Transparency Initiative,” ACHI. July 12, 2022. Accessed July 27, 2022. Available [here](#).

<sup>80</sup> “Arkansas Healthcare Transparency Initiative Expands to Include New Datasets,” ACHI. July 16, 2019. Accessed July 27, 2022. Available [here](#). “Incarcerations Declined After Crisis Stabilization Unit Intervention, ACHI Study Finds,” ACHI. November 16, 2020. Accessed July 27, 2022. Available [here](#).

<sup>81</sup> “The New England States’ All-Payer Report on Primary Care Payments,” NESCSO. December 22, 2020. Accessed July 27, 2022. Available [here](#).

<sup>82</sup> “Total Cost of Care Multi-State Project: Colorado Results,” CIVHC. February 2018. Accessed August 28, 2022. Available [here](#).

“Healthcare Affordability: Data is the Spark, Collaboration is the Fuel,” NRHI. November 8, 2021. Accessed August 28, 2022. Available [here](#).

<sup>83</sup> “Prices Paid to Hospitals by Private Health Plans,” RAND Corporation. 2022. Accessed July 27, 2022. Available [here](#).

<sup>84</sup> “Producing Comparable Cost and Quality Results From All-Payer Claims Databases,” American Journal of Managed Care. May 2019. Accessed July 27, 2022. Available [here](#).

<sup>85</sup> “Advancing a National Health Data Agenda: Realizing the Promise of All Payer Claims Databases,” Manatt Health. March 2022. Accessed July 27, 2022. Available [here](#). “Enhancing the Value of Coverage Through Transparency: How APCDs Can Support Insurance Regulation,” RWJF/Manatt Health. November 2018. Accessed July 27, 2022. Available [here](#). “Advancing a National Health Data Agenda: Realizing the Promise of All Payer Claims Databases,” RWJF/Manatt Health. March 2, 2022. Accessed July 27, 2022. Available [here](#).

<sup>86</sup> “APCD Showcase,” APCD Council. Accessed May 25, 2022. Available [here](#).

<sup>87</sup> “State All-Payer Claims Databases: Tools for Improving Health Care Value, Parts 1 and 2,” The Commonwealth Fund. December 2020. Accessed July 27, 2022. Available [here](#) and [here](#), respectively.

<sup>88</sup> “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,” RAND Health/Assistant Secretary for Planning and Evaluation. June 2021. Accessed July 27, 2022. Available [here](#). “Linking State Health Care Data to Inform Policymaking: Opportunities and Challenges,” RAND Health/ASPE. June 2022. Accessed July 27, 2022. Available [here](#).

<sup>89</sup> “Assessing the Feasibility of a Sustainable Alaska All-Payer Claims Database,” Alaska Healthcare Transformation Project/Freedman HealthCare. December 9, 2020. Accessed July 27, 2022. Available [here](#). “A Health Information Blueprint for Missouri,” Midwest Health Initiative. May 25, 2022. Accessed July 27, 2022. Available [here](#).

<sup>90</sup> “The Future of State All Payer Claims Databases (APCDs),” Journal of Health Policy, Politics, and Law. September 7, 2022. Accessed November 17, 2022. Available [here](#). Readers may also benefit from SHADAC’s previous publication: “Making Use of All-Payer Claims Databases for Health Care Reform Evaluation,” SHADAC. July 2014. Accessed July 27, 2022. Available [here](#).

<sup>91</sup> In [Massachusetts](#), for example, payers are expected to submit the following files: medical claims, pharmacy claims, dental claims, member eligibility, provider, product, and benefit plan control totals. States have also built on the APCD data collection process to request additional information from payers, including alternative payment model (APM)/payment arrangement information (e.g., [Colorado](#), [Oregon](#)) and PBM contracting information (e.g., [Colorado](#)).

<sup>92</sup> For example, medical claims file frequencies vary from monthly (e.g., [Massachusetts](#)) to quarterly (e.g., [Oregon](#)); supplemental or less traditional files (e.g., APM files) are often requested on a quarterly or annual basis.

<sup>93</sup> “APCD Common Data Layout (APCD-CDL™),” APCD Council. Accessed May 25, 2022. Available [here](#).

<sup>94</sup> The CDL was based upon the most common data elements found in existing states’ APCD data submission guides.

<sup>95</sup> For example, one payer reported that Texas has added 28 new fields to the member eligibility file. For more information, see “Texas Common Data Layout,” UTHealth School of Public Health. Accessed May 25, 2022. Available [here](#).



<sup>96</sup> “New Hampshire Comprehensive Health Care Information System: Data Submission Manual,” Milliman MedInsight. February 1, 2021. Accessed July 27, 2022. Available [here](#).

<sup>97</sup> CHCIS is stewarded by New Hampshire’s Department of Health and Human Services in partnership with its Insurance Department.

<sup>98</sup> Unless other submission requirements apply. See “22 CCR § 97310. Plan Size Thresholds,” California Code of Regulations. Accessed May 31, 2022. Available [here](#).

<sup>99</sup> For example, analysis of Medicaid program data may require access to fields including, but not limited to, eligibility category and state/end dates, dual-eligibility status, and crossover claim indicator(s).

<sup>100</sup> “Massachusetts All-Payer Claims Database, Calendar Year (CY 2020), 2016-2020 Documentation Guide,” CHIA. Accessed May 25, 2022. Available [here](#).

<sup>101</sup> CMS/Medicare FFS data has a greater time lag than those of direct commercial claims submissions.

<sup>102</sup> “All-Payer Claims Database Development Manual,” West Health/APCD Council. March 4, 2015. Accessed July 24, 2022. Available [here](#).

<sup>103</sup> “All-Payer Claims Database Development Manual,” West Health/APCD Council. March 4, 2015. Accessed July 24, 2022. Available [here](#).

<sup>104</sup> “Arkansas APCD Data Request Pricing and Data Use Resources,” ACHI. Accessed July 25, 2022. Available [here](#). Dataset allows for minor data selection criteria, no custom programming. Contact ACHI for rate estimates.

<sup>105</sup> “Data Access Fees,” CIVHC. Accessed July 25, 2022. Available [here](#). Data set cost is an estimate of baseline pricing. Standard and customized reports may be available at lower rates. Contact CIVHC for rate estimates.

<sup>106</sup> “FOI and Data Requests: All-Payer Claims Database (“APCD”) Data Request Form,” Connecticut State (CT) Office of Health Strategy (OHS). Accessed July 25, 2022. Available [here](#). Rates show for nonprofit/education purchaser for initial extract. Initial extract may comprise multiple years of data. Contact CT OHS for rate estimates.

<sup>107</sup> “Delaware Health Care Claims Database Fee Schedule – FY23,” Delaware Health Information Network. Accessed July 25, 2022. Available [here](#). Minimum rate shown for grant-funded researchers for a low complexity annual fee, single data extract for a single approved use. Contact DHIN for rate estimates.

<sup>108</sup> “Administrative Bulletin 17-06. 957 CMR 5.00: Health Care Claims, Case Mix and Charge Data Release Procedures. All-Payer Claims Data Fee Schedule.” CHIA. July 1, 2018. Accessed July 25, 2022. Available [here](#). Dental File available for only \$1,000. Contact CHIA for rate estimates.

<sup>109</sup> “MCDB Data Release,” Maryland Health Care Commission. Accessed July 25, 2022. Available [here](#).

<sup>110</sup> “Pricing Information: Requests for Other Data Files, Reports, or Tables,” MHDO. Accessed July 25, 2022. Available [here](#). Showing prices for Restricted Level II and Level III Data for nonprofit/educational users. Contact MHDO for rate estimates.

<sup>111</sup> “APAC Data Requests Fact Sheet,” Oregon Health Authority (OHA). Accessed July 25, 2022. Available [here](#). Showing prices for limited data sets. Contact OHA for rate estimates.

<sup>112</sup> “HealthFacts RI Database,” State of Rhode Island (RI) Department of Health (DOH). Accessed July 25, 2022. Available [here](#). Price shown for a single-use, single organizational license. Contact RI DOH for rate estimates.

<sup>113</sup> “Access to Data Series: All Payer Claims Database,” UT Office of Health Care Statistics (OHCS). Accessed July 25, 2022. Available [here](#). Contact UT OHCS for rate estimates.

<sup>114</sup> Limiting data collection to only that which is necessary to support identified use cases was cited by one reviewer as a core principle of good privacy management, dating back to its establishment in the 1977 “Belmont Report.” For more information, see “The Belmont Report,” HHS. April 18, 1979. Accessed August 5, 2022. Available [here](#)). However, to serve as flexible state data resources, state APCD agencies must bear the responsibility of collecting and protecting more data than may be used for any one existing or prospective use case. State APCD agencies are, in turn, responsible for ensuring that those seeking extracts from an APCD are either receiving data that cannot jeopardize an individual’s privacy, or are receiving the minimum necessary data required to support their legally allowable purposes and have appropriate data security protections and destruction protocols in place to ensure individuals’ privacy is maintained.

<sup>115</sup> “All-Payer Claims Databases: The Balance Between Big Healthcare Data Utility and Individual Health Privacy,” The Source on Healthcare Price & Competition. October 2017. Accessed July 25, 2022. Available [here](#). However, if a state agency that operates an APCD is the same state agency that operates a health plan and a health care provider—as may be the case when the APCD agency is the same entity as the state Medicaid agency—then the state may include employees who operate the APCD as part of the state’s HIPAA covered entity.

<sup>116</sup> Whether directly or through state regulations that mirror HIPAA requirements (e.g., CO/CIVHC).

<sup>117</sup> “State All Payer Claims Databases Advisory Committee Report with Recommendations Under Section 735 of the Employee Retirement Income Security Act of 1974,” DOL, SAPCDAC. Accessed May 25, 2022. Available [here](#).

<sup>118</sup> “HIPAA for Professionals,” HHS Health Information Privacy. Accessed July 25, 2022. Available [here](#).

<sup>119</sup> “Introduction to HIPAA,” Manatt Health. June 29, 2022. Accessed July 25, 2022. Available upon request. Later amended by HITECH to include the Breach Notification Rule.

<sup>120</sup> “State All Payer Claims Databases Advisory Committee Report with Recommendations Under Section 735 of the Employee Retirement Income Security Act of 1974,” DOL, SAPCDAC. Accessed May 25, 2022. Available [here](#).

<sup>121</sup> “Achieving States’ Goals for All-Payer Claims Databases,” Anthem Public Policy Institute. July 2018. Accessed July 25, 2022. Available [here](#).

<sup>122</sup> “Fact Sheet: Minnesota All Payer Claims Database Submission Requirements and Variance Management,” Minnesota DOH. Accessed July 25, 2022. Available [here](#).

<sup>123</sup> “Federal Policy Options to Realize the Potential of APCDs,” USC-Brooking Schaeffer Initiative for Health Policy. October 2020. Accessed July 25, 2022. Available [here](#).

<sup>124</sup> “Key Regulatory Issues Facing APCD States Post *Gobeille v. Liberty Mutual*,” University of New Hampshire, the APCD Council, NAHDO, and the National Academy for State Health Policy (NASHP). 2016. Accessed July 25, 2022. Available [here](#).

<sup>125</sup> “State All Payer Claims Databases Advisory Committee Report with Recommendations Under Section 735 of the Employee Retirement Income Security Act of 1974,” DOL, SAPCDAC. Accessed May 25, 2022. Available [here](#).

<sup>126</sup> “All-Payer Claims Databases: The Balance Between Big Healthcare Data Utility and Individual Health Privacy,” The Source on Healthcare Price & Competition. October 2017. Accessed July 25, 2022. Available [here](#).

<sup>127</sup> “*Dobbs, State Health Officer of the Mississippi Department of Health, et al. v. Jackson Women’s Health Organization, et al.*,” U.S. Supreme Court. June 24, 2022. Accessed July 25, 2022. Available [here](#).

<sup>128</sup> “*Dobbs* and the future of health data privacy for patients and healthcare organizations,” Journal of the American Medical Informatics Association. September 1, 2022. Accessed July 25, 2022. Available [here](#).

<sup>129</sup> Non-HIPAA covered entities, including state APCDs, are often covered under other federal and state regulations that may protect how data may be collected and used. Federal and state legislators nationally are considering whether and how to strengthen these protections.

<sup>130</sup> For example: “Secretary’s Report. Health Care Under Attack: An Action Plan to Protect and Strengthen Reproductive Care,” HHS. August 2022. Accessed July 25, 2022. Available [here](#).

<sup>131</sup> For example: “H.R. 8152 – American Data Privacy and Protection Act,” U.S. Congress. July 20, 2022. Accessed July 25, 2022. Available [here](#).

<sup>132</sup> For example: “A.B. 1666 – Abortion: civil actions,” California Assembly. Filed June 24, 2022. Accessed July 25, 2022. Available [here](#). “A.B. 2091 – Disclosure of information: reproductive health and foreign penal civil actions,” California Assembly. Enrolled September 2, 2022. Accessed September 5, 2022. Available [here](#).

<sup>133</sup> “APCD Data Privacy & Security Subcommittee – Meeting 1,” CT OHS/CedarBridge Group. April 26, 2019. Accessed July 25, 2022. Available [here](#).

<sup>134</sup> For an inventory of many states’ rules for APCD data collection, see: “Claims Data Collection Rules,” APCD Council. Accessed July 25, 2022. Available [here](#).

<sup>135</sup> “Minnesota’s All-Payer Claims Database Frequently Asked Questions,” Minnesota Department of Health. February 2015. Accessed July 25, 2022. Available [here](#).

<sup>136</sup> “Impact of De-Identification on Master Patient Index and Data Linkages,” Massachusetts CHIA. August 2020. Accessed July 25, 2022. Available [here](#).

<sup>137</sup> Referenced data collection excludes ERISA-preempted self-insured data, as previously discussed.

<sup>138</sup> “The Massachusetts All-Payer Claims Database Medical Claim File Submission Guide,” The Commonwealth of Massachusetts CHIA. February 2019. Accessed June 5, 2022. Available [here](#).

<sup>139</sup> “Utah All-Payer Claims Database (APCD) Data Submission Guide: Version 1,” Utah Department of Health, OHCS, Center for Health and Data Informatics. February 2020. Accessed June 5, 2022. Available [here](#).

<sup>140</sup> An APCD’s utility to understand a cross-state region’s health status and its barriers to engaging with the health care system would be further limited by a state-resident and state-sitused requirement for data collection (e.g., addressing health inequities in the lower Mississippi River Delta, understanding health system utilization patterns across New York-New Jersey-Connecticut, Oregon-Washington, Maryland-Virginia-Washington, D.C.). For more information on the health inequities in the Delta and the need for more comprehensive data, see “States of Despair: Understanding Declining Life Expectancy in the United States – Responses from Dr. Joe Thompson, ACHI, Executive Director,” Alliance for Health Policy. August 22, 2018. Accessed July 5, 2022. Available [here](#).

<sup>141</sup> An inventory of state claims data collection rules can be found here: “Claims Data Collection Rules,” APCD Council. Accessed July 25, 2022. Available [here](#).

<sup>142</sup> “APCD Data Privacy & Security Subcommittee – Meeting 1,” CT OHS/CedarBridge Group. April 26, 2019. Accessed July 25, 2022. Available [here](#).

<sup>143</sup> “Summary of the HIPAA Security Rule,” HHS Health Information Privacy. Accessed July 25, 2022. Available [here](#).

<sup>144</sup> “All-Payer Claims Databases: The Balance Between Big Healthcare Data Utility and Individual Health Privacy,” The Source on Healthcare Price & Competition. October 2017. Accessed July 25, 2022. Available [here](#).

<sup>145</sup> “All-Payer Claims Databases: The Balance Between Big Healthcare Data Utility and Individual Health Privacy,” The Source on Healthcare Price & Competition. October 2017. Accessed July 25, 2022. Available [here](#).

<sup>146</sup> “Security and Privacy,” Maine Health Data Organization. Accessed October 5, 2022. Available [here](#). “NIST 800-53 Rev.5, Security and Privacy Controls for Information Systems and Organizations,” NIST. September 2020. Accessed July 24, 2022. Available [here](#).

<sup>147</sup> “Security and Privacy,” Maine Health Data Organization. Accessed October 5, 2022. Available [here](#).

<sup>148</sup> For more information on de-identification practices and the safe harbor, see: “Releasing APCD Data: How States Balance Privacy and Utility,” Freedman HealthCare. March 2017. Accessed July 25, 2022. Available [here](#).

<sup>149</sup> For an inventory of many states’ rules for APCD data release, see “Claims Data Release Rules,” APCD Council. Accessed July 25, 2022. Available [here](#).

<sup>150</sup> “Releasing APCD Data: How States Balance Privacy and Utility,” Freedman HealthCare. March 2017. Accessed July 24, 2022. Available [here](#).

<sup>151</sup> “State All-Payer Claims Databases: Tools for Improving Health Care Value, Part 2: Appendix A,” The Commonwealth Fund. December 2020. Accessed July 24, 2022. Available [here](#).

“Recommendation Report for Expanded Access to the Minnesota All Payer Claims Database: Initial Findings,” MDH. February 2022. Accessed July 24, 2022. Available [here](#).

“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: Table C.1,” RAND Health Care. June 2021. Accessed July 24, 2022. Available [here](#).

<sup>152</sup> Florida’s APCD was established on July 1, 2016 per CS/CS/HB 1175, signed by the Governor on April 14, 2016. The bill directed the Florida Agency for Health Care Administration (AHCA) [Center for Health Information and Transparency](#) to competitively procure a vendor—ultimately the HCCI—to “provide a user-friendly, Internet-based platform which allows a consumer to research and compare the cost of health care services and procedures ... [and] establish and maintain a Florida-specific dataset of healthcare claims information available to the public and any interested party.” The bill allowed payers to designate submitted information as “trade secret” to maintain its confidentiality. The [Florida Health Price Finder](#) was established to support the first requirement, though public access to the claims information appears to remain limited to the [downloadable](#) limited public use files with commercial price and procedure care bundle data—though [notes](#) from the Center’s State Consumer Health Information and Policy Advisory Council’s September 29, 2021 meeting indicate a “public facing analytics tool,” HealthInsights, is presently “under development and testing” to further expand data access. For more information on the Florida APCD’s establishment, see “Final Bill Analysis: CS/CS/BH 1175,” Florida House of Representatives. April 15, 2016. Accessed July 24, 2022. Available [here](#).

<sup>153</sup> AHCA is also responsible for annually reporting on price variation in the state. HCCI regularly supports such analyses. For more information, see “State Consumer Health Information and Policy Advisory Council, Florida Health Price Finder Results Summary PY 2018/2019 Data Update,” AHCA/HCCI. Slides 5–28. June 16, 2021. Accessed July 24, 2022. Available [here](#).

<sup>154</sup> “Minnesota’s All-Payer Claims Database Frequently Asked Questions,” MDH. February 2015. Available [here](#).

<sup>155</sup> In 2014, the Minnesota Legislature [directed](#) the MN MHD to explore expanding access to MN APCD data. The workgroup convened and [recommended](#) that “Minnesota should move forward with developing a system of expanded uses ... starting with access to Public Use Files and summary data tables and transitioning to more ‘high stakes’ uses over time,” which the Legislature [directed](#) the creation of in 2015. A limited set of summary-level [Public Use Files](#) are available from the MN MHD free of charge and upon request. Through its 2021 legislative session, the Minnesota Legislature again directed MDH to consider options to expand access to the MN APCD and propose recommendations back to it by December 15, 2022; MDH published [initial findings](#) as it works toward that deadline and, in September 2022, released a series of [Public Use File Dashboards](#).

<sup>156</sup> CO APCD established by legislation passed in 2010.

<sup>157</sup> “Plain-talk Blog: Once You’ve Seen One APCD...You’ve Seen One APCD!” CIVHC. August 30, 2021. Accessed July 24, 2022. Available [here](#).

<sup>158</sup> CIVHC’s Data Release and Review Committee reviews all requests that contain PHI to ensure compliance with federal and state privacy regulations. For more information on CIVHC’s nonpublic data releases, see “Contents of the CO APCD and How Data is Released,” CIVHC. July 18, 2021. Accessed July 24, 2022. Available [here](#). “Non-Public Data,” CIVHC. Accessed February 27, 2022. Accessed July 24, 2022. Available [here](#).

<sup>159</sup> Massachusetts Division of Health Care Finance and Policy started collecting detailed payer claims data and established a charter for an APCD in 2009, and released its first APCD-like data set with private payer data in the summer of 2012. CHIA’s establishment in 2013 brought with it broader regulatory authority and financial support, enabling it to significantly expand and redefine APCD data collection thereafter. For more on Massachusetts’ APCD history, please see “Overview of the Massachusetts All-Payer Claims Database,” Massachusetts CHIA. September 2016. Accessed July 24, 2022. Available [here](#).

<sup>160</sup> In recent years, CHIA has paused on releasing data sets that contain payment information to “market participants.” For more information on the MA APCD access requirements, see: “MA APCD Application Documents,” MA CHIA. Accessed February 27, 2022. Available [here](#). “957 CMR 5.00: Health Care Claims, Case Mix and Charge Data Release Procedures,” December 14, 2017. Accessed July 24, 2022. Available [here](#).

<sup>161</sup> “Resultant Research Using the MA APCD and CHIA’s Case Mix Data,” MA CHIA. Accessed February 27, 2022. Available [here](#). Example of CHIA APCD reporting: “Enrollment Trends,” MA CHIA. Accessed July 24, 2022. Available [here](#).

<sup>162</sup> “APCD Data Privacy & Security Subcommittee – Meeting 1,” CT OHS/CedarBridge Group. April 26, 2019. Accessed July 25, 2022. Available [here](#).

<sup>163</sup> “Application for Massachusetts All-Payer Claims Data (Non-Government),” MA CHIA. Accessed July 24, 2022. Available [here](#).

<sup>164</sup> Requests involving MassHealth (Medicaid) data also require MassHealth review.

<sup>165</sup> “Agreement for Use of Center for Health Information and Analysis (CHIA) Data Containing Protected Health Information,” MA CHIA. Accessed July 24, 2022. Available [here](#).

<sup>166</sup> Connecticut’s APCD agency, the Office of Health Strategy, follows a similar protocol for its APCD releases.

<sup>167</sup> “Colorado All Payer Claims Database Data Release Application,” CIVHC. Accessed July 25, 2022. Available [here](#).

<sup>168</sup> “Standard Data Sets,” CIVHC. Accessed February 27, 2022. Available [here](#). “Custom Data Sets,” CIVHC. Accessed February 27, 2022. Available [here](#).

<sup>169</sup> “DRRC Criteria for the Release of Custom Reports and De-identified Data from the Colorado All Payer Claims Database (APCD),” CIVHC. Accessed February 27, 2022. Available [here](#). “Data Release Policies and Procedures Data Release Review Committee (DRRC) Colorado All Payer Claims Database (APCD),” CIVHC. Accessed February 27, 2022. Available [here](#).

<sup>170</sup> “APCD DUA,” CIVHC. Accessed February 27, 2022. Available [here](#).

<sup>171</sup> “How long does it take?” CIVHC. Accessed February 27, 2022. Available [here](#).

<sup>172</sup> “HPD Data Release Committee,” CA HCAI. Accessed July 24, 2022. Available [here](#).

<sup>173</sup> “CA Health & Safety Code § 127673.83 (2021),” CA Legislature. 2021. Accessed July 27, 2022. Available [here](#).

<sup>174</sup> “APCD Data Privacy & Security Subcommittee – Meeting 1,” CT OHS/CedarBridge Group. April 26, 2019. Accessed July 25, 2022. Available [here](#).

<sup>175</sup> “Security and Privacy,” Maine Health Data Organization. Accessed October 5, 2022. Available [here](#). MHDO stores SUD-released data in a separate protected data environment, which is available to “authorized MHDO data users under the terms and conditions of payment, health care operations, and other health care related activities.” For more information on MHDO’s data release protocols, see “90-590 – Maine Health Data Organization – Chapter 120: Release of Data to the Public,” MHDO. Accessed July 24, 2022. Available [here](#).

<sup>176</sup> Required to link member records between payers, including where a portion of an individual’s benefits may be “carved out” from the primary payer’s submissions (e.g., pharmacy benefits), and over time, as members transition between plans and payer types.

<sup>177</sup> Required to reliably link provider records to patient services and link various provider records together to overarching physician groups or health systems.

<sup>178</sup> For example, Freedman HealthCare manages Delaware’s Office of Value Based Health Care Delivery for the Department of Insurance. For more information, see: “FHC’s Primary Care Investment and Transformation Projects,” Freedman Healthcare. Accessed July 25, 2022. Available [here](#).

<sup>179</sup> “The Importance of Health Data Utilities in Supporting Public Health,” Indiana Health Information Exchange. 2022. Accessed August 20, 2022. Available [here](#).

<sup>180</sup> For example, CIVHC has partnered with the Human Services Research Institute (HSRI) to develop an “APCD in a Box” opportunity for smaller, prospective APCD states, where CIVHC would scale its infrastructure to support new state APCD data collection.

<sup>181</sup> Assessment of publicly available information supplemented by reviewer feedback. Please check with vendors directly for most accurate information about the services they can provide.

<sup>182</sup> “Data management” may include, but not be limited to, the following functions: data collection, security, quality assurance, data set creation, linking, and exchange. “Analytics” may include, but not be limited to, the following functions: data analysis, reporting, data visualization, and dashboard development, as well as supporting internal agency APCD capacity-building. “Technical assistance and other services” may include, but not be limited to, the following functions: legal and regulatory consultation, stakeholder support, data release process support, data security maintenance, enterprise strategy support, and data governance.

<sup>183</sup> May include data governance support.

<sup>184</sup> Delaware’s APCD is also managed by its independent nonprofit, the Delaware Health Information Network (DHIN), with technology vendor support. For more information, see “Legislative Report on Outsourcing OHCS: Pros, Cons & Investigation of Federal Matching,” Utah Department of Health. April 27, 2020. Available [here](#).

<sup>185</sup> Scope variations can include data collection, editing, and quality assurance activities; level of payer and provider engagement in data validation (e.g., some states allow providers to flag suspect data); the required interface for analytic users (e.g., raw files or a user-friendly “data cube”); whether any analytic “value added” fields are added (e.g., clinical groupers) or functions performed (e.g., master member indexing); and whether activities are undertaken to maintain regulatory compliance (e.g., member de-identification).

<sup>186</sup> Estimate informed by comments from subject matter expert reviewers.

<sup>187</sup> Vendor contracting should be paired with strong vendor-transition requirements to avoid potential mission-critical data access and service disruptions, should a vendor change become necessary.

<sup>188</sup> Manatt analysis of data available from the following reports, as well as original research and estimates based on state health data organizations’ budgets, where discrete data was not available:

“State All-Payer Claims Databases: Tools for Improving Health Care Value, Part 1,” The Commonwealth Fund. December 2020. Accessed July 27, 2022. Available [here](#).

“White Paper: Overview of All-Payer Claims Databases in the United States - A Report for Employers and Other Health Care Purchasers,” Employers’ Forum of Indiana. February 9, 2020. Available [here](#).

“Legislative Report on Outsourcing OHCS: Pros, Cons & Investigation of Federal Matching,” Utah Department of Health. April 27, 2020. Accessed July 25, 2022. Available [here](#).

“Assessing the Feasibility of a Sustainable Alaska All-Payer Claims Database,” Freedman Healthcare. December 9, 2020. Accessed July 25, 2022. Available [here](#).

<sup>189</sup> Massachusetts’ CHIA is a commonly cited exception to this range, with a proposed direct budgetary appropriation of just over \$31 million in State Fiscal Year 2023. However, the majority of CHIA’s expenditures are used non-APCD-related public reporting and program analyses, which it is required to undertake annually. For more information, see: “H2 – 4100-0060,” Massachusetts Legislature. Accessed July 25, 2022. Available [here](#).

<sup>190</sup> “HB 1175,” Florida House of Representatives. March 11, 2016. Accessed July 25, 2022. Available [here](#).

<sup>191</sup> One reviewer noted that the ongoing costs represented a “conservative estimate” and likely did not include substantive analytic work using the infrastructure.

<sup>192</sup> Given their heavy reliance on General Fund dollars, state APCD agencies are often required to be immediately responsive to near-term and pressing legislative priorities, and may need to delay investments in longer-term use cases.

<sup>193</sup> CHIA budget proposal developed with the input of its external Oversight Council.

“957 CMR 3.00: Assessment on Certain Health Care Providers and Surcharge Payors,” Commonwealth of Massachusetts. Accessed on May 25, 2022 via CHIA Regulations [website](#). Available [here](#).

“Oversight Council,” CHIA. Accessed on May 25, 2022. Available [here](#).

<sup>194</sup> “90-590, Maine Health Data Organization, Chapter 10: Determination of Assessments,” MHDO. Accessed July 24, 2022. Available [here](#).

<sup>195</sup> “Funding for APCD’s via CMS Medicaid Match,” Freedman Healthcare and CIVHC. February 20, 2018. Accessed July 25, 2022. Available [here](#).

“6 Tips for Exploring “Medicaid Match” Funding for APCDs,” APCD Journal. March 1, 2018. Accessed July 25, 2022. Available [here](#).

<sup>196</sup> The availability and level of FFP are negotiated between the state Medicaid agency and CMS through the Advanced Planning Documents (PAPD). Potential FFP rates are governed by: the level of shared administrative functions and services an APCD can provide a Medicaid program, the allocation of cost for those services, and the matching fund opportunity pursued. OMB established the federal government’s cost principles for such funding opportunities (see OMB Circular A-87), though waivers have been granted in recent years to encourage broader health and human services program administrative integration. For more information on FFPs and cost allocation methodologies, see:

“Medicaid Administrative Claiming,” CMS. Accessed July 25, 2022. Available [here](#).

“OMB Circular A-87,” OMB. Accessed July 25, 2022. Available [here](#).

“Tri-Agency Letter,” HHS. August 10, 2011. Accessed July 25, 2022. Available [here](#).

“Supplemental Guidance on Cost Allocation for Exchange and Medicaid Information Technology (IT) Systems,” HHS. October 5, 2012. Accessed July 25, 2022. Available [here](#).

“Financing Shared Administrative Functions Between State-Based Marketplaces and State Medicaid Programs: Cost Allocation Methodologies,” State Health and Value Strategies (SHVS)/Center for Health Care Strategies (CHCS). September 2015. Available [here](#).

<sup>197</sup> “2021 CO APCD Annual Report, Appendix D: History of Funding for the CO APCD,” CIVHC. Accessed May 25, 2021. Available [here](#).

<sup>198</sup> “Washington State All-Payer Claims Database and Lead Organization biennial report,” Washington State Health Care Authority. March 31, 2022. Accessed July 25, 2022. Available [here](#).

<sup>199</sup> “Making Use of All-Payer Claims Databases for Health Care Reform Evaluation,” SHADAC. July 2014. Accessed July 25, 2022. Available [here](#).

<sup>200</sup> “State Innovation Models Initiative: General Information,” CMMI. Accessed July 25, 2022. Available [here](#).

<sup>201</sup> “Rhode Island State Innovation Model (SIM) Test Grant: Operational Plan,” Rhode Island Executive Office of Health and Human Services. April 25, 2018. Accessed July 25, 2022. Available [here](#).

“The New York State Health Innovation Plan,” New York State Department of Health. Accessed July 25, 2022. Available [here](#).

“Delaware State Innovation Model (SIM) Final Report (2015-2019),” Delaware Department of Health and Social Services, Delaware Health Care Commission. 2019. Accessed July 25, 2022. Available [here](#).

<sup>202</sup> “State Health Care Innovation Plan: Final Status Report,” Washington State Health Care Authority. July 31, 2019. Accessed July 25, 2022. Available [here](#).

<sup>203</sup> “New Mexico’s All Payer Claims Database,” New Mexico Department of Health. July 7, 2021. Accessed July 25, 2022. Available [here](#).

<sup>204</sup> “State All-Payer Claims Database (APCD) Snapshots: Center for Consumer Information & Insurance Oversight (CCIIO) Cycle III Rate Review Grants Fund New APCDs,” SHADAC. March 10, 2014. Accessed July 25, 2022. Available [here](#).

<sup>205</sup> “About the Arkansas APCD,” ACHI. Accessed July 25, 2022. Available [here](#).

“Hawai’i All-Payer Claims Database,” Telecommunications and Social Informatics Research Program/Pacific Health Informatics and Data Center. Accessed July 25, 2022. Available [here](#).

<sup>206</sup> “All-Payer Claims Databases,” AHRQ. Accessed July 25, 2022. Available [here](#).

<sup>207</sup> See Grant, “Improving the Utility and Comparability of Health Care Data for Health Services Research,” via AHRQ’s “Grants by State.” Accessed May 25, 2022. Available [here](#).

<sup>208</sup> For example: “Peterson Center on Healthcare Partners with Rhode Island and Brown University on Innovating Healthcare Data Transparency Initiative,” Peterson Center on Healthcare. August 23, 2018. Accessed July 15, 2022. Available [here](#).

<sup>209</sup> “Multi-Payer Claims Database/Task 12: Summary Report and Recommended Design Option,” Avalere Health/ASPE. May 2010. Accessed July 25, 2022. Available [here](#).

<sup>210</sup> “Overview of the Multi-Payer Claims Database (MPCD),” OptumInsight/ASPE. June 7, 2011. Available [here](#).

<sup>211</sup> “Supporting Comparative Effectiveness Research with Claims Data: Federal Efforts to Develop a Multi-Payer Claims Database,” Brookings. November 7, 2011. Accessed May 25, 2022. Available [here](#).

“Beta Testing the Multi-Payer Claims Database (MPCD),” ASPE. Accessed August 7, 2022. Available [here](#).

<sup>212</sup> “S. 1895 - Lower Health Care Costs Act,” U.S. Congress. July 8, 2019. Accessed July 25, 2022. Available [here](#).

“LHCC Act Opening Statement,” Congressional Record. June 27, 2019. Accessed November 5, 2022. Available [here](#).

<sup>213</sup> TPAs may provide administrative services and network access to self-insured employers.

<sup>214</sup> As noted by one reviewer, as the Senate committee of jurisdiction for ERISA, the HELP Committee sought to mitigate ERISA-preemption concerns through the LHCC Act’s reciprocal data exchange model. Unlocking ERISA-preempted data for direct collection by state APCDs may require DOL regulatory changes, and perhaps legislative action since the Supreme Court’s ruling in *EPA v. West Virginia*.

<sup>215</sup> “Letter to Chairman Alexander re: Policy Options from Insurance Regulators,” New Hampshire Insurance Department. January 23, 2017. Accessed November 5, 2022. Available [here](#).

<sup>216</sup> “Letter to Chairman Alexander re: Policy Options to Slow the Increase of Health Care Costs and Could Gain Bipartisan Support,” American Enterprise Institute/Brookings Institution. March 1, 2019. Accessed November 5, 2022. Available [here](#).

<sup>217</sup> “Letter to Chairman Alexander and Ranking Member Murray in response to LHCC Act,” ERIC. June 5, 2019. Accessed November 5, 2022. Available [here](#).

<sup>218</sup> “Letter to Chairman Alexander and Ranking Member Murray in response to LHCC Act,” American Benefits Council. June 5, 2019. Accessed November 5, 2022. Available [here](#).

<sup>219</sup> “Letter to Chairman Alexander in response to LHCC Act,” PBGH. June 25, 2019. Accessed November 5, 2022. Available [here](#).

<sup>220</sup> “Letter to Chairman Alexander and Ranking Member Murray in response to LHCC Act,” American Hospital Association. June 5, 2019. Accessed November 5, 2022. Available [here](#).

<sup>221</sup> “Letter to Chairman Alexander and Ranking Member Murray in response to LHCC Act,” America’s Physician Groups. June 10, 2019. Accessed November 5, 2022. Available [here](#).

<sup>222</sup> “Letter to Chairman Alexander and Ranking Member Murray in response to LHCC Act,” U.S. Chamber of Commerce. June 17, 2019. Accessed November 5, 2022. Available [here](#).

<sup>223</sup> “AHIP Comments on Lower Health Care Costs Act,” AHIP. June 26, 2019. Accessed November 5, 2022. Available [here](#). AHIP’s comment letter to the committee is behind a member-only paywall and unavailable to the public.

<sup>224</sup> “Hospitals, doctors raise alarm over surprise billing legislation advanced by Senate lawmakers,” Fierce Healthcare. June 26, 2019. Accessed November 5, 2022. Available [here](#).

“Conservatives unhappy with surprise billing approach,” Axios. June 27, 2019. Accessed November 5, 2022. Available [here](#).

<sup>225</sup> In late 2020, HR 8967 was also introduced in the House to establish a federal APCD and referred to various committees for further consideration; further action was not taken. For more information, see “H.R.8967 - Federal All-Payer Claims Database Act of 2020,” U.S. Congress. December 15, 2020. Accessed July 25, 2022. Available [here](#).



<sup>226</sup> “H.R. 6004 – Transparency and Accountability in Health Care Costs and Prices Act of 2020,” U.S. Congress. February 27, 2020. Accessed May 25, 2022. Available [here](#).

<sup>227</sup> “H.R. 8967 – Federal All-Payer Claims Database Act of 2020,” U.S. Congress. December 15, 2020. Accessed May 25, 2022. Available [here](#).

<sup>228</sup> States were further incented to align cross-state data applications by having their grant applications “prioritize[d]” for review.

<sup>229</sup> “H.R. 133 – Consolidated Appropriations Act, 2021,” U.S. Congress. December 27, 2020. Accessed May 25, 2022. Available [here](#).

<sup>230</sup> “State All Payer Claims Databases Advisory Committee (SAPCDAC),” U.S. Department of Labor. Accessed May 27, 2022. Available [here](#).

<sup>231</sup> “Departments of Labor, Health and Human Services, and Education, and Related Agencies Appropriation Bill, 2023,” U.S. House of Representatives. June 2022. Accessed July 20, 2022. Available [here](#).

<sup>232</sup> For more information, see “Appropriations Committee Releases Fiscal Year 2023 Labor, Health and Human Services, Education, and Related Agencies Funding Bill,” U.S. House of Representatives, Appropriations Committee. June 22, 2022. Accessed July 20, 2022. Available [here](#).

<sup>233</sup> “Department of Health and Human Services, Fiscal Year 2023, Agency for Healthcare Research and Quality,” AHRQ. 2022. Accessed August 7, 2022. Available [here](#).

<sup>234</sup> “H.R.34 - 21st Century Cures Act,” U.S. Congress. December 13, 2016. Accessed July 27, 2022. Available [here](#).

<sup>235</sup> “CMS Interoperability and Patient Access Final Rule (CMS-9115-F),” Federal Register. May 1, 2020. Accessed July 27, 2022. Available [here](#).

“21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program,” Federal Register. May 1, 2020. Accessed July 27, 2022. Available [here](#).

<sup>236</sup> “The Patient Protection and Affordable Care Act,” U.S. Congress. March 23, 2010. Accessed July 23, 2022. Available [here](#).

<sup>237</sup> Updated in 2021: “Calendar Year 2022 Hospital Outpatient Prospective Payment and Ambulatory Surgical Center Payment Systems and Quality Reporting Programs; Price Transparency of Hospital Standard Charges; Radiation Oncology Model Final Rule with comment period (CMS-1753-FC),” Federal Register. November 16, 2021. Accessed August 1, 2022. Available [here](#). For additional information, see CMS’ “Hospital Price Transparency” information, Available [here](#).

<sup>238</sup> “Transparency in Coverage Final Rule (CMS-9915-F),” CMS. October 29, 2020. Accessed July 23, 2022. Available [here](#).

<sup>239</sup> “Assessing Implementation of Hospital Price Transparency,” New York State Health Foundation/Manatt Health. January 2022. Accessed July 23, 2022. Available [here](#).

<sup>240</sup> “The New England States’ All-Payer Report on Primary Care Payments,” NESCSO. December 22, 2020. Accessed July 27, 2022. Available [here](#).

<sup>241</sup> Includes select examples from the following publication, shared by a reviewer: “Voluntary Submission of ERISA Self-Funded Data,” HCAI. July 2022. Accessed August 5, 2022. Available [here](#).

<sup>242</sup> i.e., FFS-equivalent values.

<sup>243</sup> “States of Despair: Understanding Declining Life Expectancy in the United States – Responses from Dr. Joe Thompson, ACHI, Executive Director,” Alliance for Health Policy. August 22, 2018. Accessed July 5, 2022. Available [here](#).

<sup>244</sup> “Minutes of the Senate Committee on Health and Human Services, Senate Bill 472,” State of Nevada Legislature, Senate Committee on Health and Human Services. April 10, 2019. Accessed July 24, 2022. Available [here](#). Emphasis added.

<sup>245</sup> For example, Tennessee’s recent APCD proposal confronted strong legislative resistance in the Assembly’s Insurance Subcommittee as members elevated concerns about the collection and handling of Tennesseans’ PHI.

<sup>246</sup> Nevada's Governor has already signed legislation that would allow for the establishment of an APCD "to the extent that federal money is available for this purpose." See: "Senate Bill No. 40," Nevada Legislature. Approved by the Governor on June 4, 2021. Accessed July 27, 2022. Available [here](#).

<sup>247</sup> While many APCD states are now leveraging federal matching funds (see Section III.C), a number of states are still hesitant to partner with their states' Medicaid agencies to submit applications for funding. Further, states are applying for matching funds using different rationales and for divergent amounts. Updated guidance could strengthen the case for states to apply for federal matching funds and the consistency in the submissions CMS receives for consideration.

<sup>248</sup> See MES governing statutes, accessed July 15, 2022: "Social Security Act, Section 1903(a)(3) and (7)," Federal Regulations. Available [here](#); "42 CFR Part 433," Federal Regulations. Available [here](#); State Medicaid Director letter, August 16, 2016, Available [here](#); "CMS Data and System Director Testimony," National Committee on Vital and Health Statistics, Available [here](#).

<sup>249</sup> CMS may also require state APCDs support state Medicaid agencies in ways they are solely equipped to support, including: providing claims/encounter histories for Medicaid beneficiaries upon enrollment to support more effective risk stratification and proactive care management, reducing costs; linking dual-eligible beneficiary records (Medicaid/Medicare) to support dual demonstration rate-setting or Medicaid/Medicare plan care management; supporting Medicaid quality improvement and reform evaluations; and supporting cross-departmental analyses of market-wide concerns (e.g., public health crises, program reforms). State Medicaid agencies could be held responsible for reporting on these endeavors and their direct impact on Medicaid program efficiency and effectiveness on an annual basis.

<sup>250</sup> Most state APCDs still collect data on state-funded self-insured lives (e.g., state employee health benefit plans).

<sup>251</sup> "*Gobeille, Chair of the Vermont Green Mountain Care Board v. Liberty Mutual Insurance Co.*," Supreme Court. October Term, 2015. Decided March 1, 2016. Accessed July 27, 2022. Available [here](#).

<sup>252</sup> "Employer Health Benefits: 2021 Annual Survey," Kaiser Family Foundation. 2021. Accessed July 27, 2022. Available [here](#).

<sup>253</sup> "2020 Employer Health Benefits Survey," Kaiser Family Foundation. October 8, 2020. Accessed July 27, 2022. Available [here](#).

<sup>254</sup> "Necessary versus sufficient claims data," HCCI. July 2016. Available [here](#). Note: This was an early study based on a convenience sample.

<sup>255</sup> "Report to Congress on a study of the large group market," US Department of Health and Human Services (HHS); DOL. 2011. Accessed July 27, 2022. Available [here](#).

<sup>256</sup> Nine percent of all large firms reported "contributing information" to a state APCD.

<sup>257</sup> Fourteen percent reported seeing "a great deal" of value, and 37% saw "somewhat" value. Self-insured employers would likely find even greater value in **complete** state APCDs and the ability to access standardized APCD data from multiple states through a centralized process.

<sup>258</sup> "2022 Employer Health Benefits Survey," KFF. October 27, 2022. Accessed November 19, 2022. Available [here](#).

<sup>259</sup> Justice Kennedy was joined by Justices Roberts, Thomas, Breyer, Alito, and Kagan on the opinion. Justices Thomas and Breyer also filed concurring opinions. Justices Ginsburg filed a dissenting opinion, which Justice Sotomayor joined.

<sup>260</sup> "*Gobeille, Chair of the Vermont Green Mountain Care Board v. Liberty Mutual Insurance Co.*," Supreme Court. October Term, 2015. Decided March 1, 2016. Accessed July 27, 2022. Available [here](#).

<sup>261</sup> "Form 5500 Series," DOL. Accessed July 25, 2022. Available [here](#).

<sup>262</sup> "Proposed Rule RIN 1210-AB63, Annual Reporting and Disclosure," Department of Labor, Employee Benefits Security Administration. July 11, 2016. Accessed July 25, 2022. Available [here](#).

<sup>263</sup> "Labor, IRS Propose New Health Plan Reporting Requirements; CMS Makes Its Case On Cost Sharing," Health Affairs. July 12, 2016. Accessed July 25, 2022. Available [here](#).

- <sup>264</sup> “Comments on Department of Labor Notice of Proposed Rulemaking, Docket # EBSA-2016-0010, RIN 1210-AB63,” NASHP/NAHDO/APCD Council. September 15, 2016. Accessed July 25, 2022. Available [here](#).
- <sup>265</sup> “Increasing Price Transparency in Health Care: Key Themes and Policy Options from a Technical Expert Panel,” RAND Corporation. 2021. Accessed July 25, 2022. Available [here](#).
- <sup>266</sup> “APCD Common Data Layout (APCD-CDL™),” APCD Council. Accessed May 25, 2022. Available [here](#).
- <sup>267</sup> “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,” RAND Health/Assistant Secretary for Planning and Evaluation. June 2021. Accessed July 27, 2022. Available [here](#).
- <sup>268</sup> “State All Payer Claims Databases Advisory Committee Report with Recommendations Under Section 735 of the Employee Retirement Income Security Act of 1974,” DOL, SAPCDAC. Accessed May 25, 2022. Available [here](#).
- <sup>269</sup> “Bringing Health Care Prices to Light,” National Conference of State Legislatures (NCSL). February 2021. Accessed July 25, 2022. Available [here](#).
- <sup>270</sup> “Federal Policy Options to Realize the Potential of APCDs,” USC-Brooking Schaeffer Initiative for Health Policy. October 2020. Accessed July 25, 2022. Available [here](#).
- <sup>271</sup> “State All Payer Claims Databases Advisory Committee Report with Recommendations Under Section 735 of the Employee Retirement Income Security Act of 1974,” DOL, SAPCDAC. Accessed May 25, 2022. Available [here](#).
- <sup>272</sup> “Efforts to Ease the Sharing of Data: Policies & Program Design,” CIVHC, presented at NAHDO Conference. October 25, 2022. Accessed October 25, 2022. Not yet publicly available.
- <sup>273</sup> “Self-Insured Claims in the CO APCD,” CIVHC. Accessed October 15, 2022. Available [here](#).
- <sup>274</sup> “Efforts to Ease the Sharing of Data: Policies & Program Design,” CIVHC, presented at NAHDO Conference. October 25, 2022. Accessed October 25, 2022. Not yet publicly available.
- <sup>275</sup> “Georgia Senate Bill 1,” LegiScan. January 12, 2021. Accessed July 15, 2022. Available [here](#).
- <sup>276</sup> “Letter to Chair of Georgia Senate Finance Committee, Chuck Hufstetler,” ERIC. February 1, 2021. Accessed July 25, 2022. Available [here](#).
- <sup>277</sup> “SAPCDAC Meeting Minutes,” DOL/SAPCDAC. June 17, 2021. Accessed October 15, 2022. Available [here](#).
- <sup>278</sup> “Comment on Form 5500 – Annual Reporting and Disclosure,” The ERISA Industry Committee. December 5, 2016. Accessed October 15, 2022. Available [here](#).
- <sup>279</sup> “*West Virginia et al. v. Environmental Protection Agency et al.*,” The Supreme Court of the United States. June 30, 2022. Accessed October 15, 2022. Available [here](#).
- <sup>280</sup> “Comment Letter Re: Self-Insured Plan Reporting to State All Payer Claims Databases (APCDs),” American Benefits Council. December 21, 2021. Accessed October 15, 2022. Available [here](#).
- <sup>281</sup> “Comment Letter Re: Lower Health Care Cost Act,” Consumers First (American Academy of Family Physicians; American Benefits Council; American Federation of State, County and Municipal Employees; Families USA; First Focus Campaign for Children; PBGH). June 15, 2019. Accessed October 15, 2022. Available [here](#).
- <sup>282</sup> “State All Payer Claims Databases Advisory Committee Report with Recommendations Under Section 735 of the Employee Retirement Income Security Act of 1974,” DOL, SAPCDAC. Accessed May 25, 2022. Available [here](#).
- <sup>283</sup> “Research Paper No. 334: ERISA as a Barrier for State Health Care Transparency Efforts,” UC Hastings Law. 2019. Accessed July 25, 2022. Available [here](#).

<sup>284</sup> “Section 204 of Title II of Division BB of the CAA added parallel provisions at section 9825 of the Internal Revenue Code[,],...section 725 of the Employee Retirement Income Security Act (ERISA), and section 2799A-10 of the Public Health Service Act (PHS Act), which require group health plans and health insurance issuers offering group or individual health insurance coverage to annually submit to the Departments certain information about prescription drug and health care spending.” Per “Prescription Drug and Health Care Spending (86 FR 66662),” Federal Register. November 23, 2021. Accessed October 15, 2022. Available [here](#).

<sup>285</sup> “Prescription Drug Data Collection (RxDC),” CMS. Accessed August 25, 2022. Available [here](#).

<sup>286</sup> “Prescription Drug Data Collection (RxDC) Reporting Instructions,” CMS. June 29, 2022. Accessed September 15, 2022. Available [here](#).

<sup>287</sup> “*West Virginia et al. v. Environmental Protection Agency et al.*,” The Supreme Court of the United States. June 30, 2022. Accessed October 15, 2022. Available [here](#).

<sup>288</sup> This strategy includes the development of state APCD standards across lines-of-business for efficiency purposes. See solution strategies for [Opportunity #3.1](#) for additional detail.

<sup>289</sup> HHS may build on infrastructure and processes already established. See “Standard-Setting and Related Organizations,” HHS. Accessed November 19, 2022. Available [here](#).

<sup>290</sup> For example, if a state Medicaid managed care program introduces a new eligibility classification code, the state should not need to wait for a normal, full review process to conclude to begin requesting that data from payers. The standards process should include an expedited review pathway that would allow states to make nonstructural change additions to a list of “allowable” fields without significant delay.

<sup>291</sup> The APCD CDL is currently maintained by the APCD-CDL Maintenance Committee, “an advisory committee of volunteer state agencies, payers, and vendors” that considers changes to the APCD-CDL on a biennial cycle. “Data Maintenance Requests” are able to be submitted by anyone using the CDL. For more information, see: “APCD Common Data Layout,” APCD Council. Accessed November 15, 2022. Available [here](#).

<sup>292</sup> “State All Payer Claims Databases Advisory Committee Report with Recommendations Under Section 735 of the Employee Retirement Income Security Act of 1974,” DOL, SAPCDAC. Accessed May 25, 2022. Available [here](#).

<sup>293</sup> One reviewer noted that DOL advanced similar requirements for retirement plans - in that instance, capping fees that may be levied.

<sup>294</sup> “Total Number of Medicare Beneficiaries: 2020,” KFF. Accessed February 7, 2022. Available [here](#).

<sup>295</sup> “Confidentiality of Substance Use Disorder Patient Records,” Federal Register. July 15, 2020. Accessed July 27, 2022. Available [here](#).

<sup>296</sup> NAHDO and the APCD Council elevated the issue to SAMHSA in letters and discussions on several occasions in 2020, 2021, and 2022 on behalf of state APCD agencies.

<sup>297</sup> State APCD agencies may also need to overcome additional state-level regulations prohibiting SUD data exchange.

<sup>298</sup> “H.R. 8967 – Federal All-Payer Claims Database Act of 2020,” U.S. Congress. December 15, 2020. Accessed May 25, 2022. Available [here](#).

<sup>299</sup> Submitting or sharing all health care claims data with respect to the Medicare program under Title XVIII of the Social Security Act (42 U.S.C. 1395 et seq.) and the Medicaid program under Title XIX of such Act (42 U.S.C. 1396 et seq.).

<sup>300</sup> Administered by the Office of Personnel Management (OPM). The OPM Office of Healthcare and Insurance oversees the FEHB Program, and until 2021 administered its Health Claims Data Warehouse (HCDW). The HCDW was replaced by the more limited, enrollment data-focused Health Insurance Data Warehouse (HIDW) after concerns about data security and data collection authority arose. FEHB Program data for a national HDO may need to be sought directly from plans. For more information on the HIDW, see “Privacy Impact Assessment for Health Insurance Data Warehouse (HIDW),” OPM. July 2, 2021. Accessed July 27, 2022. Available [here](#). For information on stakeholders’ HCDW concerns, see “Audit Finds Security Issues With Database Already Opposed by Plans Citing HIPAA,” Cosmos. August 31, 2018. Accessed July 27, 2022. Available [here](#).

<sup>301</sup> Administered by the Secretary of Defense under Chapter 55 of Title 10, United States Code.

<sup>302</sup> “Confidentiality of Substance Use Disorder Patient Records,” Federal Register. July 15, 2020. Accessed July 27, 2022. Available [here](#).

<sup>303</sup> APCD users may also seek information on plan design and information on provider relationships, which may not be standardized across plans and may be captured and recorded differently by each plan.

<sup>304</sup> “Measuring Non-Claims-Based Primary Care Spending,” Milbank Memorial Fund. April 2021. Accessed November 19, 2022. Available [here](#).

<sup>305</sup> “Payer Data Submitter Group,” MHDO. December 14, 2021. Accessed November 15, 2022. Available [here](#).

<sup>306</sup> “Oregon’s Health Care Payment Arrangements in 2020,” OHA. June 2022. Accessed November 15, 2022. Available [here](#).

<sup>307</sup> “Non-Claims Data in the CO APCD,” CIVHC. Accessed November 15, 2022. Available [here](#).

“Alternative Payment Models in Colorado, 2018-2020,” CIVHC. August 2022. Available [here](#).

<sup>308</sup> “Payer Data Submitter Group,” MHDO. December 14, 2021. Accessed November 15, 2022. Available [here](#).

<sup>309</sup> Financial vulnerabilities of many primary care providers were revealed during the pandemic, when patient visits plummeted, resulting in a corresponding, sharp decrease in practitioner financials.

<sup>310</sup> “Activating Health Data to Achieve Health Equity: Recommended Strategies for REaL and SOGI Data,” Blue Shield of California/ Define Ventures. June 2022. Accessed November 15, 2022. Available [here](#).

“Collection of Race and Ethnicity Data for Use by Health Plans to Advance Health Equity Opportunities, Barriers, and Solutions,” Urban Institute. July 2022. Accessed November 15, 2022. Available [here](#).

<sup>311</sup> “Medicaid Administrative Data: Challenges with Race, Ethnicity, and Other Demographic Variables,” KFF. April 28, 2022. Accessed November 15, 2022. Available [here](#).

“Inaccuracies in Medicare’s Race and Ethnicity Data Hinder the Ability To Assess Health Disparities,” HHS Office of Inspector General. June 15, 2022. Accessed November 15, 2022. Available [here](#).

“Improving Race and Ethnicity Data Collection: A First Step to Furthering Health Equity Through the State-Based Marketplaces,” The Commonwealth Fund. June 9, 2022. Accessed November 19, 2022. Available [here](#).

“Federal Action Is Needed to Improve Race and Ethnicity Data in Health Programs,” Grantmakers in Health. October 2021. Accessed November 15, 2022. Available [here](#).

<sup>312</sup> “Current and Innovative Practices in Data Quality Assurance and Improvement National Association of Health Data Organizations,” NAHDO. 2019. Accessed November 15, 2022. Available [here](#).

<sup>313</sup> “Social Determinants of Health: APCD and Hospital Discharge Data Standards and Collection Practices,” NAHDO. November 2022. Accessed November 19, 2022. Available [here](#).

<sup>314</sup> “State All Payer Claims Databases Advisory Committee Report with Recommendations Under Section 735 of the Employee Retirement Income Security Act of 1974,” DOL, SAPCDAC. Accessed May 25, 2022. Available [here](#).

<sup>315</sup> “Measuring Non-Claims-Based Primary Care Spending,” Milbank Memorial Fund. April 2021. Accessed November 19, 2022. Available [here](#).

<sup>316</sup> For example, see “Plaintalk Blog: Collecting Race and Ethnicity Data in the CO APCD,” CIVHC. Accessed November 15, 2022. Available [here](#).

<sup>317</sup> “Unlocking Race and Ethnicity Data to Promote Health Equity in California: Proposals for State Action,” Manatt Health. April 19, 2021. Accessed June 5, 2022. Available [here](#).

<sup>318</sup> The X12 Insurance Subcommittee (X12N) is the DSMO for HIPAA claims transaction standards. For more information, see: “X12 Purpose and Scope Statement,” X12. Accessed February 21, 2022. Available [here](#).

<sup>319</sup> ASC X12 developed the PACDR in 2021 for professional, institutional, and dental transactions to allow payers to translate HIPAA-compliant provider transactions (e.g., 837 formats) into formats more acceptable to state APCDs. New York is the only state to require PACDR submission. For more information on the PACDR, see “Written Comment of Gary Beatty, ASC X12 Chair,” HHS National Committee on Vital and Health Statistics (NCVHS) Panel on Claims-based Databases. June 14, 2016. Available [here](#).

<sup>320</sup> Operating rules for electronic data interchange (EDI) transactions are managed by the Council for Affordable Quality Healthcare (CAQH) Committee on Operating Rules for Information Exchange (CORE) on behalf of the U.S. Department of Health and Human Services. For more information, see: “Regulations and Guidance, Administrative Simplification: Operating Rules Overview,” CMS. Accessed February 21, 2022. Available [here](#).

<sup>321</sup> The New York Department of Health used the PACDR as its APCD data submission standard. Per one reviewer, data submitters reported persistent challenges in complying with the PACDR’s hierarchical format, given how most of the requested data was stored in their data warehouses.

<sup>322</sup> “Regulations and Guidance, Administrative Simplification: Code Sets Overview,” CMS. Accessed February 21, 2022. Available [here](#).

“HIPAA and Administrative Simplification: Adopted Standards and Operating Rules,” CMS. Accessed February 21, 2022. Available [here](#).

<sup>323</sup> Payers, it should be noted, require similar fields as they use their transaction data for similar analyses, though each have customized analytic fields and methods.

<sup>324</sup> Payer asked to remain anonymized. Though similar feedback was provided in: “Achieving States’ Goals for All-Payer Claims Databases,” Anthem Public Policy Institute. June 2018. Accessed July 27, 2022. Available [here](#).

<sup>325</sup> In [Massachusetts](#), for example, payers are expected to submit the following files: medical claims, pharmacy claims, dental claims, member eligibility, provider, product, and benefit plan control totals. States have also built on the APCD data collection process to request additional information from payers, including alternative payment model (APM)/payment arrangement information (e.g., [Colorado](#), [Oregon](#)) and PBM contracting information (e.g., [Colorado](#)).

<sup>326</sup> For example, medical claims file frequencies vary from monthly (e.g., [Massachusetts](#)) to quarterly (e.g., [Oregon](#)); supplemental or less traditional files (e.g., APM files) are often requested on a quarterly or annual basis

<sup>327</sup> “Data Submission Guide Version 13,” CIVHC. January 2022. Accessed November 15, 2022. Available [here](#).

“File Layouts for Appendices A-G,” Oregon Health Authority, APAC. Version 2021. 1.1. Accessed November 15, 2022. Available [here](#).

<sup>328</sup> “The Massachusetts All-Payer Claims Database Member Eligibility File Submission Guide,” The Commonwealth of Massachusetts CHIA. February 2019. Accessed July 27, 2022. Available [here](#).

“ACHI APCD Atlas, APCD Layouts and Definitions: Member Enrollment Data,” ACHI. May 4, 2021. Accessed July 27, 2022. Available [here](#).

<sup>329</sup> As payers maintain federal/state regulatory claims data standards, it may result in new conflicts with state APCD submission requirements.

<sup>330</sup> “Statement on Behalf of UnitedHealthcare to the State All Payer Claims Databases Advisory Committee,” United Healthcare. May 19, 2021. Accessed July 27, 2022. Available [here](#).

<sup>331</sup> For example, payers may not have APCD fields including Federal Information Processing Standards (FIPs) County Codes, Medicaid AID Categories, Employment Status, Member PCP Effective Dates, or Claim Version Number. These fields may be requested and even required by some state APCDs. For payers that do not have this data, they may manufacture “dummy” data to pass completeness checks.

<sup>332</sup> May be also represented by the National Association of Insurance Commissioners (NAIC)

<sup>333</sup> One possible model for developing data standards could involve having a central APCD SAG to confirm standardization proposals and identify and adjudicate cross-file and -line-of-business issues, with multiple subcommittees designated to specific file types and/or lines-of-business.

<sup>334</sup> It is important to note that payers may be limited in their ability to address some state APCD completeness or quality concerns. Payers are dependent on the claims and encounters they receive from delegated payers and providers, which may not meet state APCD standards.

<sup>335</sup> NAHDO, the APCD Council, and states recognized this issue when developing the APCD-CDL.

<sup>336</sup> Assumes a national data collection and dissemination model is not pursued.

<sup>337</sup> "Health Care Payments Data (HPD)," California HCAI. Accessed May 25, 2022. Available [here](#).

<sup>338</sup> "Data Security and the CO APCD," CIVHC. Accessed November 15, 2022. Available [here](#).

<sup>339</sup> Over time, if a common application increases data demand and related revenues, states may pursue regulatory alignment.

<sup>340</sup> State APCD agencies are frequently required by their state legislatures or stakeholders to investigate questions using specific inclusion/exclusion criteria.

<sup>341</sup> "Report of Colorado Primary Care Spending and Alternative Payment Model Use, 2018-2020," CIVHC. November 2021. Accessed July 27, 2022. Available [here](#).

<sup>342</sup> "2020 Primary Care Spending in Oregon Report Executive Summary," OHA. June 2022. Accessed July 27, 2022. Available [here](#).

<sup>343</sup> For Colorado's and Oregon's primary care analyses, for example, included populations, payers, and time frames, as well as provider types, may have diverged: Colorado's analysis includes behavioral health providers, while Oregon's does not. "Report of Colorado Primary Care Spending and Alternative Payment Model Use, 2018-2020," CIVHC. November 2021. Accessed July 27, 2022. Available [here](#). "Primary Care Spending in Oregon: Methodology," OHA. June 2022. Accessed July 27, 2022. Available [here](#).

<sup>344</sup> Freedman HealthCare and Onpoint regularly convene a subset of state APCD leaders to discuss similar issues.

<sup>345</sup> Reviewers noted that state APCD budgets represent a fraction of what private for-profit sector entities—from stewards of private claims databases to payers and providers—spend on market data collection and analytics.

<sup>346</sup> See referenced section for source notes.

<sup>347</sup> In a grant funding application to The Commonwealth Fund, HCCI also noted that costs for including new national claims data from Blue Health Intelligence (BHI) would cost approximately \$3 million annually for 2020 through 2022: \$2 million annually for data acquisition and \$1 million annual for infrastructure costs. For more information, see: "Health Care Cost Institute Data Infrastructure Funding, 2021," The Commonwealth Fund. March 4, 2021. Accessed November 15, 2022. Available [here](#).

<sup>348</sup> "Health Care Cost Institute Inc. – Form 990, Line 18," GuideStar. 2020. Accessed November 15, 2022. Available [here](#).

"FAIR Health – Form 990, Line 18," GuideStar. 2020. Accessed November 15, 2022. Available [here](#). FAIR Health supports a broad spectrum of analytic activities and users nationally.

<sup>349</sup> "IBM Explores Sale of IBM Watson Health," WSJ. February 18, 2021. Accessed November 15, 2022. Available [here](#).

<sup>350</sup> "Mission & History," CHIA. Accessed May 25, 2022. Available [here](#).

<sup>351</sup> For more information on state healthcare cost growth benchmarking reporting, see Manatt's work here: "The Manatt State Cost Containment Update," Manatt Health. Accessed May 25, 2022. Available [here](#).

<sup>352</sup> "2015 Report on the Performance of the Massachusetts Health Care System – 2015 Annual Report TME Data Book," CHIA. September 2015. Available [here](#).

<sup>353</sup> "Budget cut costs state's clearinghouse for health care market data," Boston Globe. May 26, 2016. Available [here](#).

"Funding slashed for Mass. agency studying healthcare cost containment strategies," Becker's Hospital Review. July 19, 2016. Accessed July 27, 2022. Available [here](#).

<sup>354</sup> "HB 2289," Tennessee General Assembly. July 16, 2009. Accessed July 27, 2022. Available [here](#).

<sup>355</sup> “Enforcement of Tennessee’s ‘All Payer Claims Database’ Statute,” State of Tennessee Office of the Attorney General. December 7, 2016. Accessed July 27, 2022. Available [here](#).

<sup>356</sup> E.g., MHDO has a board comprised of providers, payers, consumers, and other parties providing complete transparency and accountability in budget development and assessment, which has resulted in a stable financial operating environment for the HDO over the past decade.

<sup>357</sup> “Capital Budgeting in the States,” NASBO. Spring 2014. Accessed November 15, 2022. Available [here](#).

<sup>358</sup> Though not APCD data submitters, providers typically supply the state HDO with a significant amount of data that can be paired with APCD data to create more actionable information.

<sup>359</sup> “Healthcare data scientist qualifications, skills, and job focus: a content analysis of job postings,” Journal of Informatics in Health and Biomedicine. March 1, 2019. Accessed July 27, 2022. Available [here](#).

<sup>360</sup> “Data Scientists in High Demand for Healthcare Providers, Payers,” Health IT Analytics. April 2, 2019. Accessed July 27, 2022. Available [here](#).

“48% of Businesses, Including Healthcare, Face Big Data Skills Gap,” Health IT Analytics. May 8, 2017. Accessed July 27, 2022. Available [here](#).

<sup>361</sup> “In-House Data Privacy, Cybersecurity Lawyers Are in High Demand, With Little Competition,” Legaltech News. June 8, 2020. Accessed July 27, 2022. Available [here](#).

<sup>362</sup> “Investments in the State and Local Government Workforce Will Deliver Crucial Services and Create Economic Security,” The Center for American Progress. March 25, 2022. Accessed July 27, 2022. Available [here](#).

<sup>363</sup> “Government Wage Growth Lags Private Sector by Largest Margin on Record,” Pew. February 7, 2022. Accessed July 27, 2022. Available [here](#).

<sup>364</sup> “Government can win the talent race - Here’s how,” Deloitte Insights. May 23, 2022. Accessed July 27, 2022. Available [here](#).

<sup>365</sup> “Government Is Hiring, But Faces Tough Competition for Workers,” Governing. June 1, 2021. Accessed July 27, 2022. Available [here](#).

<sup>366</sup> “National Health Expenditure Data,” CMS. Accessed May 25, 2022. Available [here](#).

<sup>367</sup> Employer sponsored insurance only. For more information, see: “2022 Employer Health Benefit Survey: Section 6: Worker and Employer Contributions for Premiums,” KFF. October 27, 2022. Accessed November 15, 2022. Available [here](#).

<sup>368</sup> “U.S. employers brace for healthcare costs to rise next 3 years,” Fierce Healthcare. September 16, 2022. Accessed November 15, 2022. Available [here](#).

<sup>369</sup> Nearly nine-in-ten covered workers (single coverage) had a deductible in 2022, another new high. For more information, see: “2022 Employer Health Benefit Survey: Section 7: Employee Cost Sharing,” KFF. October 27, 2022. Accessed November 15, 2022. Available [here](#).

<sup>370</sup> National out-of-pocket spending hit a new high in 2019. Growth was expected to have resumed in 2021, after a decrease in 2020 due to the impact of the COVID-19 pandemic. For more information, see: “Out-of-pocket spending,” Peterson-KFF Health System Tracker. Accessed November 15, 2022. Available [here](#).

<sup>371</sup> “Medicaid Enrollment & Spending Growth: FY 2022 & 2023,” KFF. October 25, 2022. Accessed November 15, 2022. Available [here](#).

<sup>372</sup> The CBO projects Medicare Mandatory Outlays will increase from \$868 billion to \$963 billion (+11%) with Offsetting Receipts growing at a faster rate (\$180 billion to \$216 billion, +20%), resulting in an overall increase of 8.6%. For more information, see: “Baseline Projections: Medicare,” CBO. May 2022. Accessed November 15, 2022. Available [here](#).

<sup>373</sup> “National Health Spending Projected to Hit \$6.8 Trillion by 2030,” Health Affairs. March 28, 2022. Accessed November 15, 2022. Available [here](#).



<sup>374</sup> “Medicaid Financing: The Basics,” KFF. May 7, 2021. Accessed November 15, 2022. Available [here](#).

“Summary: 2022 State Expenditure Report,” National Association of State Budget Officers. November 18, 2022. Accessed November 20, 2022. Available [here](#).

<sup>375</sup> “National Health Spending Projected to Hit \$6.8 Trillion by 2030,” Health Affairs. March 28, 2022. Accessed November 15, 2022. Available [here](#).

“Americans’ Challenges with Health Care Costs,” KFF, July 14, 2022. Accessed July 27, 2022. Available [here](#).

<sup>376</sup> “Achieving Racial and Ethnic Equity in U.S. Health Care,” The Commonwealth Fund, November 18, 2021. Accessed July 27, 2022. Available [here](#).

<sup>377</sup> “COVID-19 Cases and Deaths by Race/Ethnicity: Current Data and Changes Over Time,” KFF, February 22, 2022. Accessed July 27, 2022. Available [here](#).

<sup>378</sup> “How does U.S. life expectancy compare to other countries?” Peterson-KFF Health System Tracker. September 28, 2021. Accessed May 25, 2022. Available [here](#).

<sup>379</sup> Some state APCD agencies also noted that they are explicitly prohibited from sharing data with the federal government by state regulation.

<sup>380</sup> “Confidence in Institutions,” Gallup. 2022. Accessed July 27, 2022. Available [here](#).

“Trust in Government,” Gallup. 2022. Accessed July 27, 2022. Available [here](#).

<sup>381</sup> To the extent effected by operational design and not otherwise represented by the preceding questions (e.g., the importance of state data ownership).

<sup>382</sup> “Federal Policy Options to Realize the Potential of APCDs,” USC-Brooking Schaeffer Initiative for Health Policy. October 2020. Available [here](#).

<sup>383</sup> “Health Care Cost, Quality, and Equity Data Atlas Technical Feasibility Analysis,” California Health and Human Services Agency. March 1, 2017. Available [here](#).

<sup>384</sup> For an example, see “InsData User’s Manual,” NAIC. Accessed May 25, 2022. Available [here](#).

<sup>385</sup> APCD operating model changes alone cannot address all opportunities to enhance state APCD use and usefulness. Federal and state regulatory and financial support will be essential to realizing the potential utility of any national operating model.

<sup>386</sup> Assumes federal authority and willingness to require ERISA-preempted self-insured data collection by states using a common national APCD data standard. See “Model Assumptions.”

<sup>387</sup> To the extent effected by operational design and not otherwise represented by the preceding questions (e.g., the importance of state data ownership).

<sup>388</sup> The model may be similar to payer Medical Loss Ratio reporting maintained by CMS’ CCIIO “Medical Loss Ratio Data and System Resources,” CMS CCIIO. Accessed May 25, 2022. Available [here](#).

<sup>389</sup> APCD operating model changes alone cannot address all opportunities to enhance state APCD use and usefulness. Federal and state regulatory and financial support will be essential to realizing the potential utility of any national operating model.

<sup>390</sup> Assumes federal authority and willingness to require ERISA-preempted self-insured data collection by states using a common national APCD data standard. See “Model Assumptions.”

<sup>391</sup> To the extent effected by operational design and not otherwise represented by the preceding questions (e.g., the importance of state data ownership).

<sup>392</sup> “Research Methodology,” PCORI. Accessed May 25, 2022. Available [here](#).

<sup>393</sup> Standardized methodologies are a key component of this model, similar to that employed by PCORI, which advances common methodology standards to “help ensure that PCOR studies are [consistently] designed and conducted to generate the evidence needed,” and “represent minimal requirements for the design, conduct, analysis and reporting.” For more information on PCORI, see “Improving the Science and Methods of PCOR,” PCORI. August 2019. Available [here](#).

<sup>394</sup> May include solicitation of data from federally administered programs.

<sup>395</sup> Data requests may include/exclude detailed criteria around populations, payers, services, providers, and time periods. Requests may offer explicit instruction on output file format, potentially offering templates for population. Instructions may also suggest technical requirements to the extent offered by participating states, including potential field names and coding logic, based on the CDL standard; provide required analytic steps states must follow to arrive at results; and request quality control totals to confirm results.

<sup>396</sup> To the extent participating states increasingly harmonize APCD data standards to more efficiently meet federal requests, payers/TPAs may experience some level of reduced administrative burden.

<sup>397</sup> APCD operating model changes alone cannot address all opportunities to enhance state APCD use and usefulness. Federal and state regulatory and financial support will be essential to realizing the potential utility of any national operating model.

<sup>398</sup> To the extent effected by operational design and not otherwise represented by the preceding questions (e.g., the importance of state data ownership).

<sup>399</sup> FHIR API standards may require further testing and maturing before this use case can be supported.

<sup>400</sup> “Statement on Behalf of United Healthcare to the State All Payer Claims Databases Advisory Committee,” United Healthcare. May 19, 2021. Accessed July 27, 2022. Available [here](#).

<sup>401</sup> “ACA risk adjustment management: Higher EDGE-ucation,” Milliman. December 22, 2017. Accessed July 27, 2022. Available [here](#).

“BCBSA and AHIP Comments to the State All Payer Claims Databases Advisory Committee,” DOL/SAPCDAC. May 14, 2021. Accessed November 15, 2022. Available [here](#).

<sup>402</sup> “Federal Policy Options to Realize the Potential of APCDs,” USC-Brookings Schaeffer Institute for Health Policy. October 2020. Accessed July 27, 2022. Available [here](#).

<sup>403</sup> State/federal users would need to work closely with payers/TPAs to ensure PHI is available to allow for record-linking once payer data is consolidated.

<sup>404</sup> Insurance companies are not presently required to support bulk transactions using FHIR APIs.

<sup>405</sup> APCD operating model changes alone cannot address all opportunities to enhance state APCD use and usefulness. Federal and state regulatory and financial support will be essential to realizing the potential utility of any national operating model.

<sup>406</sup> Assumes federal authority and willingness to require ERISA-preempted self-insured data collection by states using a common national APCD data standard. See “Model Assumptions.”

<sup>407</sup> To the extent effected by operational design and not otherwise represented by the preceding questions (e.g., the importance of state data ownership).

<sup>408</sup> LHCC Act required delivery at cost.

<sup>409</sup> The National HDO could make local adoption of a national APCD data standard a pre-requisite for receiving data, though that requirement is not stated in this LHCC Act-based model.

<sup>410</sup> In another variation of this model, the LHCC could collect full-market data directly from payers operating in nonparticipating states, similar to that described in Model 3B.

<sup>411</sup> Unless another requirement is incorporated into the model, wherein states that are seeking National HDO data must also adopt a national data standard for their own local data collections.

<sup>412</sup> APCD operating model changes alone cannot address all opportunities to enhance state APCD use and usefulness. Federal and state regulatory and financial support will be essential to realizing the potential utility of any national operating model.

<sup>413</sup> Assumes federal authority and willingness to require ERISA-preempted self-insured data collection by states using a common national APCD data standard. See “Model Assumptions.”

<sup>414</sup> To the extent effected by operational design and not otherwise represented by the preceding questions (e.g., the importance of state data ownership).

<sup>415</sup> While the model has strong similarities to the HCUP model, it would differ in several important ways, including that it would: require state HDOs (not associations) to be the program participants; it would not require state permission for use of its data; and it would be paired with funds redistribution and potentially supplemental resourcing for capacity building (not discussed here). For more information on HCUP, see “Healthcare Cost & Utilization Project – User Manual,” AHRQ. Accessed May 25, 2022. Available [here](#).

<sup>416</sup> APCD operating model changes alone cannot address all opportunities to enhance state APCD use and usefulness. Federal and state regulatory and financial support will be essential to realizing the potential utility of any national operating model.

<sup>417</sup> Assumes federal authority and willingness to require ERISA-preempted self-insured data collection by states using a common national APCD data standard. See “Model Assumptions.”

<sup>418</sup> To the extent effected by operational design and not otherwise represented by the preceding questions (e.g., the importance of state data ownership).

<sup>419</sup> To the extent effected by operational design and not otherwise represented by the preceding questions (e.g., the importance of state data ownership).

<sup>420</sup> “S. 1895 - Lower Health Care Costs Act,” U.S. Congress. July 8, 2019. Accessed July 27, 2022. Available [here](#).

<sup>421</sup> “ONC Awards The Sequoia Project a Cooperative Agreement for the Trusted Exchange Framework and Common Agreement to Support Advancing Nationwide Interoperability of Electronic Health Information,” HHS. September 3, 2019. Accessed May 25, 2022. Available [here](#).

<sup>422</sup> “Agency for Healthcare Research and Quality: A Profile,” AHRQ. Accessed May 25, 2022. Available [here](#).

“Healthcare Cost & Utilization Project,” AHRQ. Accessed May 25, 2022. Available [here](#).

<sup>423</sup> “Confidence in Institutions,” Gallup. 2022. Accessed July 27, 2022. Available [here](#). “Trust in Government,” Gallup. 2022. Accessed July 27, 2022. Available [here](#).

<sup>424</sup> HHS may build on infrastructure and processes already established. See “Standard-Setting and Related Organizations,” HHS. Accessed November 19, 2022. Available [here](#).

<sup>425</sup> Data standards governance should include a process by which states may receive expedited reviews and approvals for the addition of state-specific codes within existing data fields.

<sup>426</sup> Assumes the DOL has agreed to promulgate data collection requirements under its regulation of ERISA plans

<sup>427</sup> One reviewer recommended a one-way hash to prevent reidentification

<sup>428</sup> Including HIPAA, the OMB circulates on deidentification, and federal data curation standards

<sup>429</sup> Federal and participating state users may be granted expedited and expanded access to data, as determined allowable by the governing body. Similar to the external user data request process, all governmental access applications would be publicly recorded.

<sup>430</sup> To avoid cannibalizing local state APCD user revenues, the National HDO may be required to redistribute a portion of its data application and access fees back to the states from which state data is being requested/released. The National HDO may be prohibited from releasing data for only one state; it may be required to redirect single-state applicants directly to the state of interest.

<sup>431</sup> “S. 1895 - Lower Health Care Costs Act,” U.S. Congress. July 8, 2019. Accessed July 27, 2022. Available [here](#).

<sup>432</sup> “Federal Policy Options to Realize the Potential of APCDs,” USC-Brookings Schaeffer Institute for Health Policy. October 2020. Accessed July 27, 2022. Available [here](#).

<sup>433</sup> “Federal Policy Options to Realize the Potential of APCDs,” USC-Brooking Schaeffer Initiative for Health Policy. October 2020. Accessed July 27, 2022. Available [here](#).

<sup>434</sup> The Governance Entity and any subcommittees or advisory groups it may form would be responsible for these responsibilities and functions.

<sup>435</sup> The National HDO governance entity may consider implementing a tiered access model over a restricted use data model. Tiered-access models require enhanced data governance, security and privacy controls, and operations to manage access, but provide open access to a broader array of data that may be used to support an expanded universe of research use cases.

<sup>436</sup> Federal budget requests would be made to AHRQ.

<sup>437</sup> May include an appointment of the Executive Director of NAHDO or the Director of the APCD Council

<sup>438</sup> Further, in light of *West Virginia v. EPA* and the recommended model’s further divestiture of data collection responsibilities from the DOL to the states, clarification and confirmation of authority would be compulsory.

<sup>439</sup> “*Gobeille, Chair of the Vermont Green Mountain Care Board v. Liberty Mutual Insurance Co.*,” Supreme Court. October Term, 2015. Decided March 1, 2016. Accessed July 27, 2022. Available [here](#).

<sup>440</sup> “Research Paper No. 334: ERISA as a Barrier for State Health Care Transparency Efforts,” UC Hastings Law. 2019. Accessed July 25, 2022. Available [here](#).

<sup>441</sup> “Comment Letter Re: Self-Insured Plan Reporting to State All Payer Claims Databases (APCDs),” American Benefits Council. December 21, 2021. Accessed October 15, 2022. Available [here](#).

<sup>442</sup> “Letter to Chairman Alexander and Ranking Member Murray in response to LHCC Act,” American Benefits Council. June 5, 2019. Accessed November 5, 2022. Available [here](#).

<sup>443</sup> “Letter to Chairman Alexander and Ranking Member Murray in response to LHCC Act,” ERIC. June 5, 2019. Accessed November 5, 2022. Available [here](#).

<sup>444</sup> “Comment on Form 5500 – Annual Reporting and Disclosure,” ERIC. December 5, 2016. Accessed October 15, 2022. Available [here](#).

<sup>445</sup> “Section 204 of Title II of Division BB of the CAA added parallel provisions at section 9825 of the Internal Revenue Code[,],...section 725 of the Employee Retirement Income Security Act (ERISA), and section 2799A-10 of the Public Health Service Act (PHS Act), which require group health plans and health insurance issuers offering group or individual health insurance coverage to annually submit to the Departments certain information about prescription drug and health care spending.” Per “Prescription Drug and Health Care Spending (86 FR 66662),” Federal Register. November 23, 2021. Accessed October 15, 2022. Available [here](#).

<sup>446</sup> For example, payers/TPAs have been observed changing employers for meeting upcoming RxDC reporting requirements, even if employers plan to “self-report” using their data that payers/TPAs administer on their behalf. One payer offers to “cover associated costs for self-funded clients so long as they have” the payer’s integrated PBM solution.

<sup>447</sup> If self-insured employers face resistance from payers/TPAs in sharing their data with third-parties—including the National HDO—at their direction or as legally required, DOL may work with ONC to clarify or expand information blocking provisions to prevent anti-competitive behavior.

<sup>448</sup> Reimbursable for approved expenditures.

<sup>449</sup> While many APCD states are now leveraging federal matching funds (see Section III.C), a number of states are still hesitant to partner with their states’ Medicaid agencies to submit applications for funding. Further, states are applying for matching funds using different rationales and for divergent amounts. Updated guidance could strengthen the case for states to apply for federal matching funds and consistency in the submissions CMS receives for consideration.

<sup>449</sup> See MES governing statutes, accessed July 15, 2022: “Social Security Act, Section 1903(a)(3) and (7),” Federal Regulations. Available [here](#); “42 CFR Part 433,” Federal Regulations. Available [here](#); State Medicaid Director letter, August 16, 2016, Available [here](#); “CMS Data and System Director Testimony,” National Committee on Vital and Health Statistics, Available [here](#).

<sup>450</sup> CMS may also require state APCDs support state Medicaid agencies in ways they are solely equipped to support, including: providing claims/encounter histories for Medicaid beneficiaries upon enrollment to support more effective risk stratification and proactive care management, reducing costs; linking dual-eligible beneficiary records (Medicaid/Medicare) to support dual demonstration rate-setting or Medicaid/Medicare plan care management; supporting Medicaid quality improvement and reform evaluations; and supporting cross-departmental analyses of market-wide concerns (e.g., public health crises, program reforms). State Medicaid agencies could be held responsible for reporting on these endeavors and their direct impact on Medicaid program efficiency and effectiveness on an annual basis.

<sup>451</sup> “A Shared Responsibility: Protecting Consumer Health Data Privacy in an Increasingly Connected World,” Manatt Health. June 2020. Accessed November 15, 2022. Available [here](#).

<sup>452</sup> In lieu of establishing another committee that must maintain compliance with the Federal Advisory Committee Act (FACA), the National HDO—via AHRQ—may inquire as to whether the NCVHS may support this undertaking.

<sup>453</sup> The National HDO’s state assessment would be done jointly with each participating state.

<sup>454</sup> Board Member, NAHDO.

<sup>455</sup> Board Member, NAHDO.

<sup>456</sup> Board Member, NAHDO.

<sup>457</sup> Former role.

<sup>458</sup> Co-chair, APCD Council.

<sup>459</sup> Board Member, NAHDO.

<sup>460</sup> Dr. Thompson’s contributions were supplemented by insights from Craig Wilson, Director of Health Policy, and Kenley Money, Director of Information Systems Architecture.

<sup>461</sup> Former role.

<sup>462</sup> Several representatives asked to remain anonymous in order to comment freely on the topic.

<sup>463</sup> Dr. Blewett is also a professor at the University of Minnesota.

<sup>464</sup> Board Member, NAHDO; President Elect, HIMSS New York.

<sup>465</sup> William Olesiuk, Director, also provided helpful comments.

<sup>466</sup> Board Member, CIVHC.

<sup>467</sup> Former role.

<sup>468</sup> Former role.

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