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Realizing the Promise of All Payer Claims Databases

A Federal and State Action Plan

EXECUTIVE SUMMARY

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Kevin serves on the board of directors of the National Association of Health Data Organizations (NAHDO) and the Association of Public Data Users.

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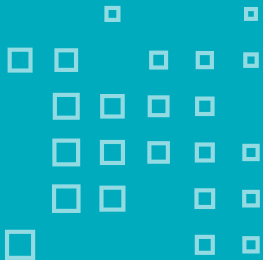


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DECEMBER 1, 2022

America spends more on health care per person than any other developed country, only to have the lowest life expectancy among them.^{1,2} Despite our expenditures—now one out of every five dollars of national income³—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.⁴ Racial and ethnic health disparities in our country are pervasive⁵ and newly compounded by COVID-19.⁶ 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.⁷

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.ⁱ 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

ⁱ See Appendix in full paper 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.⁸ 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 countries⁹
- 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 data¹⁰ 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.

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:

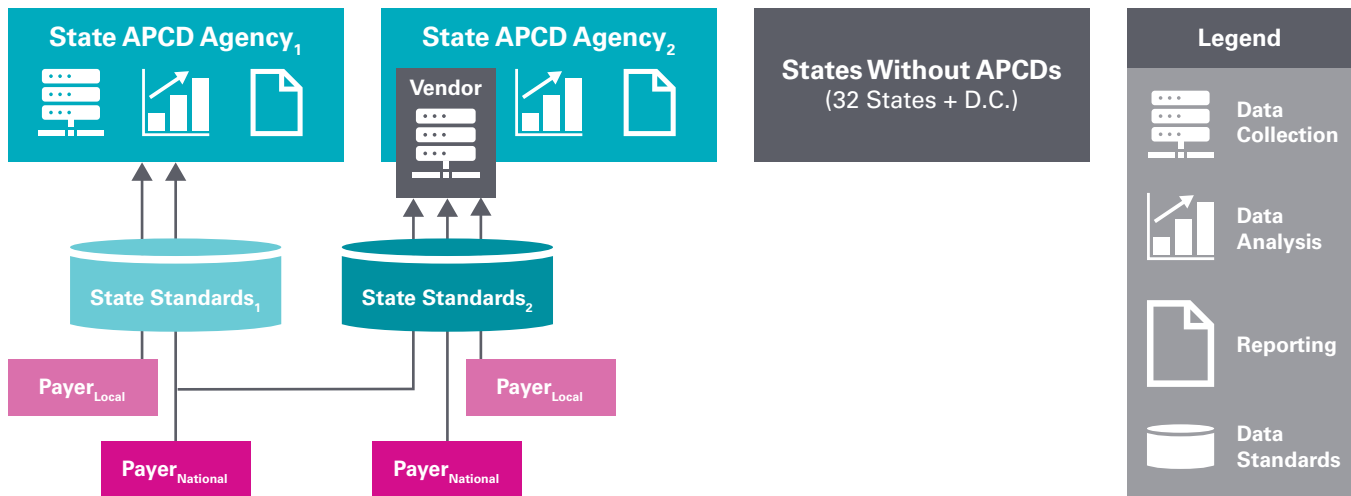
- Create and monitor baseline statistics of state health insurance coverage, service utilization, service costs, cost trends (including priority services such as primary care and behavioral health care), and health outcomes.¹¹
- Identify inequities in health system access and use as well as disparities in health condition prevalence and outcomes.¹²
- Support regulatory oversight of payers and providers, from monitoring network adequacy and mental health parity to assessing the cost impact of industry consolidation.¹³
- Identify health system failures—including coverage disruptions, excessive cost growth, service price variation, and preventable emergency department (ED) visits—to inform policy responses.¹⁴
- 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).¹⁵
- Provide purchasers, payers, and consumers with health service cost and quality information to make informed health coverage purchasing and network design decisions.¹⁶

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)

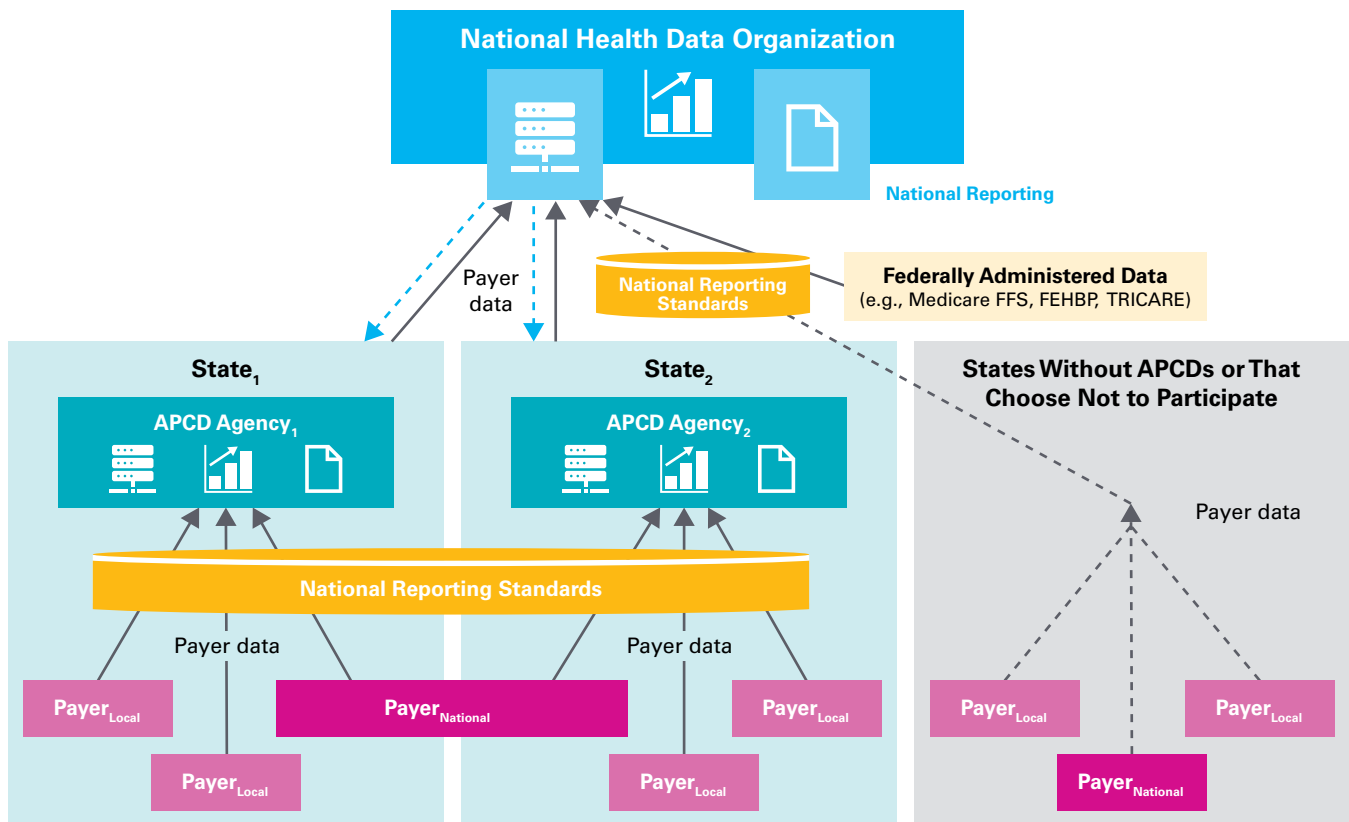
Guiding Principles for National APCD Operating Model Design	
1.	Health system data is a public good. Administrative health data is a public good that can and should be used to support health system oversight to benefit consumers.
2.	States must maintain APCD data stewardship. Many state APCDs are now 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.	Federal help is required to address APCD limitations nationally. Federal support and regulatory action are needed to resolve state APCD data completeness issues.
4.	Data standardization requires data governance. 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.	Strong state health data use requires reliable and sustained funding. 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.	Data users and changemakers need better access to APCD data. 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.	National health system transparency is needed. A national APCD is required to provide insight into national and regional health system, population health, and public health issues.
8.	Payer reporting burden must be addressed. 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.	National opportunity to strengthen APCD data protections. 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.

¹ “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](#).

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

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

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

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

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

⁷ “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](#).

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

⁹ “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](#).

¹⁰ 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.

¹¹ 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](#).

¹² 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](#).

¹³ 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](#).

¹⁴ 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](#).

¹⁵ 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](#).

¹⁶ 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](#).

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