All Payer Claims Databases: Issues and Opportunities for Health Care Cost Transparency in New Jersey

Magda Schaler-Haynes, J.D., M.P.H.
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Executive Summary

Health care costs in New Jersey are among the highest in the nation. Efforts to reveal which services, providers and populations drive up health costs are hindered by the absence of publicly available information on health insurer spending. Although payers have enjoyed access to health care claims payment data for years, consumers, employers, policymakers, providers and others have not had similar entrée to this information. Such access is considered by many to be a prerequisite to leverage consumer demand for more affordable, high value health care.

All Payer Claims Databases (APCDs) have emerged as tools to increase transparency in the historically opaque area of health claims payments. This Policy Brief provides an overview of the form, function, limitations and potential utility of an APCD, the primary vehicle available to states to gather and analyze comprehensive health care cost and utilization information across multiple payers.

Over a dozen states have enacted legislation to mandate claims reporting to APCDs and many others report some degree of APCD activity. In addition, federal agencies including the Department of Health and Human Services and the Office of Personnel Management as well as private, voluntary collaborations among payers are creating claims databases with different missions. Although voluntary data collection initiatives can offer useful insights, they do not appear to provide the comprehensive perspective gained from legislatively mandated data collection.

APCD Form and Function

In states with legislatively enacted APCDs, public, private, state and federal, medical, dental and pharmacy plans (“all payers”) must submit claims data with certain limited exceptions. Individual claims data provides a snapshot of health care utilization and spending including amounts charged by providers, amounts paid by insurers on behalf of enrollees and amounts owed by patients. Once aggregated into a database format, claims data can often answer critical baseline questions for populations such as: how much money is spent on health care within the state? Which services and which providers are most expensive? What geographic claims and cost variations exist? APCDs can track a broad range of primary and specialty care
data including payments; premiums; patient responsibilities; dates of service; diagnosis and procedure code; lab tests; and demographic information. National efforts are currently underway to standardize core APCD data elements to streamline compliance for carriers and support interstate comparisons. States can customize data collection beyond the core elements. APCD data can help tailor cost containment efforts to state-specific cost patterns.

APCD data can also be used, among other things, to provide consumers and employers with prices for health services; to facilitate quality improvement by identifying value-based spending; to identify efficient providers; to enhance market functioning and oversight; and to provide policymakers with actionable information. It may also, for example, be useful to link claims data with other formerly fragmented but complementary databases to yield comprehensive insights into health costs on an episode of care or other basis. Quality initiatives are able to sift and synthesize aggregated APCD data to generate consumer-friendly indices of value in the system. Consumers and employers with increasing responsibility for health expenses appear better equipped to seek value from providers with price information in hand before care is provided. Similarly, states and private payers faced with escalating costs can leverage claims data to pursue value-based purchasing.

Market oversight efforts such as premium rate review and risk adjustment can be improved using APCD data. Specifically, APCD data can inform trend analyses performed by government actuaries to ensure accuracy in health insurance rate setting and allow for longitudinal comparisons to evaluate premiums over time. In addition, risk adjustment required under the Affordable Care Act can use claims data to monitor market activity.

**APCD Design Includes Multiple Decisions**

Parameters such as administrative architecture; analytic priorities; cost and data control may be determined by state law or delegated to APCD administrators. State APCDs may be located within or outside the government infrastructure and can be operated by internal staff, outside vendors or a combination of both. APCD operations can be directed by a governing board or advisory committee comprised of member representatives from key stakeholders, and APCDs may issue annual reports to the governor or legislature as specified in legislation. APCDs can monitor payer compliance with data collection requirements and can issue penalties for noncompliance.

**Cost and Confidentiality**

Cost and confidentiality are among the most controversial considerations surrounding APCD development. Design parameters for both depend largely on the desired functionality of the APCD.
APCD expenses include a combination of staff salaries and vendors to: perform data collection, management and aggregation; conduct rulemaking and manage vendors; as well as hardware and software purchases. Costs are also affected by the extent to which claims and other data are already collected and maintained by carriers and states. APCD costs appear to vary considerably across states. One report examined APCD cost information from ten states and estimated first year internal costs of approximately $600,000 with annual internal maintenance costs just under $115,000. In addition to internal costs, the APCDs reported annual contractual expenses that varied between $202,000 and $1,474,000 depending on the type of contract (medians ranged from $672,000 to $859,000). States report funding APCDs from multiple sources including general state budget appropriations; federal health reform funds; carrier and facility assessments; other grant and private support and sales of limited de-identified data.

A variety of encryption and de-identification options exist to address confidentiality concerns. In addition, review boards can govern permitted access to and uses of the data. The options available to secure confidentiality depend on several factors, including the desired functionality of the data. Because data security measures impose a range of costs, budget considerations also figure in states’ confidentiality plans.

**Conclusion**

APCDs add value to health policy deliberations by closing spending information gaps. The benefits of an APCD are not without costs. Extensive experiences in other states may help New Jersey minimize those costs, assure privacy and maximize gain from an aggregated claims database should the state elect to pursue APCD development. Indeed a bill to establish an All Payer Claims Database was recently introduced in the New Jersey Assembly.\(^1\) Possible options for further exploration including public-private partnerships, assessment of existing and emerging health infrastructure initiatives, and multi-agency collaboration are reviewed in this Policy Brief.

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\(^1\) NJ Assembly No. 3603, “New Jersey All-Payer Claims Database Act” was introduced by Assemblyman Troy Singleton on December 13, 2012 and subsequently referred to the Assembly Financial Institutions and Insurance Committee.
I. Introduction

The US health care system is notable for its lack of transparency. To the extent health care costs drive health insurance premiums, the health insurance pricing landscape cannot be fully understood without health cost information. Although health insurance premium data is more widely available than ever before, data regarding underlying health care costs remains largely inaccessible. The lack of transparent cost data seemingly hinders the ability of insured health care purchasers- employers, states and individuals- to make comparisons and consider price as a factor when buying health care. To this point it has been near impossible to identify costs across payers or to establish health care spending patterns with certainty. Although fragmented data initiatives exist, health care costs in New Jersey are largely obscured from public view.

All Payer Claims Databases (APCDs) gather paid health care claims data to document the cost of health services. Through data aggregation, APCDs identify variable pricing and usage patterns across providers and variable spending patterns across multiple payers. APCDs are not cost containment mechanisms themselves, but do identify the baseline data on which the demand for high-quality, efficient health care relies. Businesses, individuals, providers and policymakers can each use APCD data as a foundation for value based health purchasing.\(^2\)

States pursue APCDs to resolve gaps in health care cost information. Currently there are more than a dozen active, state-mandated APCDs including those in Colorado, Kansas, Massachusetts, Maryland, Maine, Minnesota, New Hampshire, Oregon, Tennessee, Utah, Vermont and West Virginia. Connecticut, Virginia and New York recently passed APCD-enabling legislation. A bill to establish an All Payer Claims Database was recently introduced in the New Jersey Assembly.\(^3\) Many more states are considering the value and feasibility of establishing an APCD through stakeholder engagement and exploratory research. In 2003, Maine was the first


\(^3\) NJ Assembly No. 3603, “New Jersey All-Payer Claims Database Act” was introduced by Assemblyman Troy Singleton on December 13, 2012 and subsequently referred to the Assembly Financial Institutions and Insurance Committee, http://www.njleg.state.nj.us/2012/Bills/A4000/3603_I1.HTM.
Some states, including Wisconsin and Washington, have voluntary claims data collection efforts in place. Although voluntary and private initiatives do aggregate some data, legislative mandate appears the only way to secure near-universal APCD participation and high-quality data in standardized, usable formats.\(^6\)

APCD establishment requires financial and stakeholder support in addition to investments of time for development and implementation. States must engage in significant blueprinting: legislation, cooperation from multiple participants, fiscal support and analytic resources are all essential elements of a successful APCD initiative. Massachusetts reportedly engaged in APCD planning for approximately two years prior to the August 2010 launch of its

\(^4\) Ibid.

\(^5\) For up-to-date statistics on state efforts see All-Payer Claims Database (APCD) Council, Interactive State Report Map, last accessed May 6, 2013, http://www.apcdcouncil.org/state/map. The APCD Council is a collaboration between the University of New Hampshire and the National Association of Health Data Organizations.

New Jersey may nevertheless find an all payers claims database to be an investment worthy of scarce resources, especially because federal rate review funds allocated under the Affordable Care Act may reduce fiscal burdens for states that pursue APCD development. This Policy Brief reviews possible uses, benefits and design considerations for a New Jersey APCD with the aim of advancing robust discussion on this emerging issue.

II. What are APCDs?

All Payer Claims Databases (APCDs) are databases that aggregate insurance claim and payment information about health care services. APCDs gather data regarding claims, payments, providers, eligibility and de-identified patient information. APCDs can document health care spending patterns and are often used to reveal diseases and medical treatments that “drive” health care costs in a state. APCDs can identify health system waste and corresponding opportunities for cost containment by revealing excessive or outlier claims by service; provider and/or payer. Trends and outliers in health care cost, quality and utilization can be documented by aggregated data gathered by APCDs. In addition, APCDs can reveal variation in reimbursement across payers for specific treatments and procedures to identify, among other things, which providers are the most expensive.

When enacted by state legislation, APCDs require submission of data by public and private health, dental and pharmaceutical payers statewide. Many data-related tasks are implicit in APCD operation. By design, APCDs collect, manage, store and analyze large volumes of data. To the extent laws and regulations govern data-related tasks, APCDs may also have compliance obligations. Questions concerning confidentiality, data access, database design and staffing permeate discussions of APCD development and belong in the foreground of APCD planning.

With limited exceptions, all payers within a state are required to submit data to an APCD. Commercial carriers, Medicare and Medicaid plans, federal employee and military health plans, state employee benefit plans, as well as dental and prescription drug plans are typically mandatory APCD reporters. State APCD laws may set minimum thresholds for payer participation and may require special consideration for multistate plans. For example, in

Maine, carriers with fewer than fifty annual subscribers and in Utah carriers with fewer than 200 covered lives per year are exempt from APCD reporting. In Maryland, carriers receiving less than $1M in health insurance premiums annually are exempt from reporting data to the Maryland Medical Care Database.\textsuperscript{10} It appears considerably more difficult to obtain claims data from uninsured populations but when APCD data is combined with existing hospital discharge databases, such gaps can be minimized.

Indeed, most New England states have already established APCDs and all other neighboring states are either in implementation phases or have expressed “strong interest” in APCD development by convening workgroups to lead APCD planning.\textsuperscript{11} Notably, the costs to establish and operate an APCD appear minimal relative to health care spending overall. Should considerations progress in New Jersey, cost-benefit analysis may further aid evaluation of the commitment of scarce resources toward APCD development in light of fiscal constraints.

### III. Should New Jersey Establish an APCD?

Relative to other states, New Jersey ranks among the highest in health care costs and utilization but only average in health care quality.\textsuperscript{12} Across the political spectrum, consensus converges around the notion that current health spending is unsustainable. Without critical data documenting health costs in the state, it is difficult to conceive of cost containment initiatives tailored to the unique features of New Jersey health care markets.

In New Jersey an APCD could be used, for example, to reveal cost differences between in-network and out-of-network care; to document the volume and cost of imaging procedures and blood profiles performed across the state; to track shifting costs as hospital ownership changes; and to enable New Jersey residents to become better informed health care consumers.

To the extent that the absence of health cost data provides undue benefits to industry but disadvantages individuals, the promotion of transparency at this critical time in health spending may prove an incremental measure with broad appeal.

Data generated by APCDs could be of value to and used by:

- Employers
- Individual consumers
- Policymakers
- Payers
- Providers
- Researchers

\textsuperscript{10} National Conference of State Legislatures, “Collecting Health Data: All-Payer Claims Databases.”

\textsuperscript{11} The APCD Council tracks APCD development among the states, \textit{supra} note 5.

In turn, there are at least four reasons why New Jersey might seek to establish an APCD: to facilitate price transparency; to support quality improvement; to improve market functioning and oversight; and to provide policymakers with actionable information.

A. Price Transparency for Purchasers

Health care is unique relative to other commodities because health care consumers, to this point, have had little to no information about price prior to purchase. A market-oriented approach to curbing excessive health spending requires transparent information for multiple purchasers in the health system. APCDs offer one approach to price transparency and are the only claims reporting mechanisms mandated by state legislation. Other efforts mentioned below include carrier-administered transparency efforts, voluntary initiatives at the state level and initiatives spearheaded by private entities and the federal government. For employers, individuals and state purchasers, APCD data may offer the ability to “comparison shop” for health care services based on price and quality. In this regard, APCDs provide data with potential to support consumer-driven cost containment.

**Individual Consumers:** Insured individuals are responsible for a growing proportion of their health care costs but are usually unable to access obscured price information prior to receiving services.\(^{13}\) A recent report by the Government Accountability Office (GAO) suggests that the unavailability of meaningful price information persists due to: an inability to predict health services needed in advance of care; the impact of multiple payment arrangements including various cost sharing requirements; and legal protection for rates negotiated between payers and providers.\(^{14}\)

Although Explanation of Benefit forms convey important enrollee information about charges, allowed amounts and patient responsibilities, that information is not widely digested or available to be used as a decision factor prior to provider or health care service selection. Access to basic price information, especially when coupled with insurer-directed cost sharing incentives, may prove an essential ingredient to stimulate consumer demand for value-based health care spending.\(^{15}\) For individuals enrolled in high-deductible health plans, pricing information can have a significant impact on where one seeks care. For example, in Massachusetts, New Hampshire and Maine, consumers can now use APCD data to compare prices for high volume procedures such as colonoscopy to decide whether to seek care at a


14 Ibid.

The extent to which consumers, once equipped with price information, might consider cost before selecting a provider or health care service is unclear. Certainly for individuals who are uninsured, in high deductible health plans, or seeking out of network services, price information appears highly useful. For typical health plan enrollees, the inability to discern complex quality considerations may dampen the utility of prices alone. The most recent Bush administration directed and encouraged the availability of price information as a basic tenet of consumer dynamics, but the extent to which individual enrollees can navigate price and quality in combination with cost sharing structures and contract limitations of most health plans is not known. The potential system-wide value of price information for consumers is found where price information drives demand for high-value efficient providers. As described below, in recent years, carrier-provided transparency tools have increased significantly.

**Employers:** Employers have sought and gained access to health claims information to inform purchasing for decades. Before web-platforms simplified presentation of comparison data, large self-funded employers required third party administrators to generate reports and data for analysis. Third party administrators provided benchmarking tools to employers, and now also provide risk adjustment, risk stratification and episode grouping services based on claims data. Although initially imagined as a tool primarily valuable to state agencies and health service researchers, employers have relied and more could rely on claims data generated by the APCD platform. Among other inquiries, reports generated for employers by APCDs include: demographic analyses; medical volume and cost by age and gender; service location and cost; diagnoses by cost, utilization and encounter; top providers by cost; and pharmacy volume

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20 Ibid.  
21 Ann Boynton, deputy executive officer, benefits programs policy and planning at CalPERS stated, “CalPERS has been using a claims database for several years, and we’ve found it invaluable as a means to inform our benefit change and rate negotiation strategies. While each of our plan partners has the ability to perform robust data analysis on their segment of our members, evaluating our entire membership across carriers has provided us with invaluable insights about our overall population. We are deeply committed to the health of our members, and our decision support system is an integral part of our ability to fulfill that commitment.” Patrick Miller, *Why State All-Payer Claims Databases Matter to Employers*, Pension & Benefits Daily 1, 3 (2012).
including cost by age, gender and high-cost claimants.\textsuperscript{22}

Employers with access to cost information can more easily purchase employee health plans based on service prices. On a large scale, employer health plan selection based on cost increases demand for high-quality, efficient insurance products. Recent reports from Connecticut indicate significant employer demand for insurance products that offer price transparency such as a new program from Anthem Blue Cross and Blue Shield of Connecticut called “SmartShopper” that allows employees to compare prices and receive rebates for selecting low-cost providers.\textsuperscript{23}

\textbf{State as Purchaser:} Because the state is a purchaser of health care and health insurance, it also maintains a vested interest in cost containment efforts. To that end, APCD data can be used as it is in New Hampshire, to benchmark Medicaid payments to providers relative to commercial plans.\textsuperscript{24} New Hampshire used APCD data to document payment variation: for example, in 2006, a thirty minute office visit for a new patient was reimbursed by three commercial health plans at rates of $124; $115 and $130 respectively but New Hampshire Medicaid paid only $42.\textsuperscript{25} APCD data was used to reveal significant reimbursement disparities in New Hampshire: preventive health visits for established patients under one year of age were reimbursed by private carriers at rates of $111, $102, and $107 while New Hampshire Medicaid paid an average of $61 for the same visit.\textsuperscript{26}

New Hampshire also uses claims data collected through its APCD to compare utilization of and access to select preventive services for its Medicaid population relative to commercially insured residents and Medicaid nationally.\textsuperscript{27} By analyzing discrete preventive health services, such as blood glucose screening for diabetics or prostate screening, the review of claims data can reveal both higher and lower use of services for New Hampshire Medicaid enrollees compared to counterparts enrolled in Medicaid in other states or commercial plans within New Hampshire. Such data is essential to development of Medicaid cost savings initiatives, especially as states begin to structure such initiatives to harness costs savings associated with increased preventive health care. Given current fiscal crises faced by states, other cost containment efforts that can be designed using APCD data may also be desired. When comprehensive data is

\begin{itemize}
\item \textsuperscript{22}Miller, “Why State All-Payer Claims Databases Matter to Employers.”
\item \textsuperscript{24}Love and Steiner, \textit{Key State Health Care Databases for Improving Health Care Delivery}.
\item \textsuperscript{26}Ibid.
\end{itemize}
required to design targeted policies, the ability to link data across public and private payers can also help states overcome data gaps for populations that churn in and out of Medicaid plans.28

Once informed by cost information, employer, individual and state health care purchasers’ demand for value in health spending may emerge as a critical leverage point in health care markets.

B. Quality Improvement

In combination with other available data sources such as hospital discharge data, APCDs provide a powerful metric to evaluate quality of health services on a system-wide basis. APCD data is used by states to generate comparative report cards, to enhance effectiveness research and to identify high and low performance health plans. Indeed APCDs can be used to direct policy and programs that pinpoint quality and steer away from inefficient health delivery and financing. APCD data can be used to show variations in care within a state as well as to demonstrate the effect of clinical guidelines on care and cost. Importantly, APCD data can enable longitudinal quality comparisons- a perspective vital to policy design and evaluation.

A wide variety of quality improvement initiatives employ APCD data. The federal Agency for Healthcare Research and Quality (AHRQ) methodology was used to evaluate APCD data to identify the scope and costs of adverse drug events.29 In Utah, APCD data was used to compare costs of newborn care between groups of pregnant women that received and did not receive prenatal care. Tennessee includes transparency in quality measures; assessment of interventions on patient outcomes; evaluation of health system capacity and resources; and improved resource allocation among its objectives in passing APCD enabling legislation in 2009.30 New Hampshire is using APCD data to inform its Medicaid ACO pilot projects and Vermont can use APCD utilization data to perform modeling required for its medical home project.31

Claims data also allows for enhanced quality comparisons among provider peers. In a report generated using claims data, Vermont, New Hampshire and Maine evaluated hospital readmission rates among commercially insured populations under age 65. The data was evaluated across all three states and broken down by hospital service area to reveal fourfold variations in readmission rates within 30 days of discharge.32

28 Love et al., All-Payer Claims Databases: State Initiatives to Improve Health Care Transparency.
29 Miller et al., All-Payer Claims Databases: An Overview for Policymakers.
32 The variation spanned a high of 11.31 days and a low of 2.60 days. Karl Finison, Tri-State Variation in Health Services Utilization & Expenditures in Northern New England, Commercially Insured Population Under Age 65 in...
Revealing prices of health care services appears a reasonable first step to promote transparency, but price alone does not always communicate quality or value in health spending. In fact, the presentation to consumers of price information without a mechanism to relate prices to quality of health care services raises significant concerns even among those who appear to broadly support increased transparency.33 Although additional work is required to improve the use of quality information by consumers, the public availability of quality metrics may prompt quality improvement indirectly.34 The New Hampshire HealthCost tool provides pricing information for individual consumers and employers on a web-based platform and is now in its second iteration. New Hampshire conducts evaluation of the impact of the information on consumers in an effort to increase the utility of the HealthCost tool. Initial evaluation suggests the availability of median payments for bundled services has limited impact on prices, but the New Hampshire Insurance Department expressed its commitment to continuous improvement of this tool designed for individual consumers.35

C. Improvement of Market Function
State-administered oversight of rate setting by carriers is designed to ensure efficient market functioning and provide consumer protection.36 Under New Jersey law, carriers in the individual and small employer health insurance markets are required to submit informational rate filings with the Department of Banking and Insurance (DOBI) prior to issuing or renewing policies, or changing rates.37 In the individual and small employer health insurance markets, DOBI actuaries review rate submissions and may disapprove rates that are incomplete, not in substantial compliance, or that are inadequate or unfairly discriminatory.38 Actuaries rely on data to perform such reviews, and trend analysis is an important feature of the process. In addition, and as described further below, claims data will provide the basis on which exchange-based risk adjustment mechanisms are implemented under the Affordable Care Act (ACA).

33 Supra note 18.
34 Miller et al., All-Payer Claims Databases: An Overview for Policymakers.
37 NJSA 17B:27A-9 establishes this requirement for the individual market and N.J.S.A. 17B:27A-25f establishes this requirement in the Small Employer Health (SEH) market.
38 NJSA 17B:27A-9; NJSA 17B:27A-25.
**Rate Review:** APCD data can be used by states to enhance rate review capabilities. APCD data can improve trend analysis from rate filings and assist actuaries with verification of carrier submissions. APCDs also offer longitudinal data that can facilitate multi-year rate comparisons highly relevant to the detection of state-wide market patterns.

Vermont, for example, allocated ACA rate review grant funds to investigate utility of its multi-payer claims database known as “Vermont Healthcare Claims Uniform Reporting and Evaluation System (VHCURES),” in the rate review process. Vermont’s use of APCD data suggests claims data may improve the State’s ability to validate carrier rate filing applications, to enhance trend analysis based on rate filings, and to generate comparative data for benchmarking. Although Vermont had a highly developed rate review system in place prior to establishing VHCURES, the claims database appears to provide new insights into utilization trends and claims histories that underlie rate filings.

Vermont initiated a competitive bidding process for consulting services procured using federal rate review grant funds to identify and analyze how to use data collected by VHCURES to support its rate review objectives. Among other findings, Vermont reported that to be most useful, APCD data needs to be made directly linkable to rate review filings. In its analysis, Vermont used rate filings from two major carriers to test its ability to map rate filing data to the VHCURES system. Vermont set out to customize claims reporting to support insurance department rate review functions by “comparing the VHCURES categorization applied to the Annual Expenditure & Utilization Report and the Healthcare Report Card to the categorizations of enrollment/demographics utilization and expenditures used by the State’s actuaries; and identifying an inventory of insurance product types reported to VHCURES and evaluating the categorizations in relationship to the insurance rate review process, and identifying the categories that would be most applicable to the rate review process.”

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39 Supra note 31.
40 For example, the Vermont Department of Banking, Insurance, Securities and Health Care Administration suggests that APCD data, in the form of a healthcare utilization and expenditure report (HUER) could be used: “to understand the drivers of the claim portion of the rate increase. For example, if the claim portion of the proposed rates suggests a very high trend (12%) compared to projections from the previous year (8%), there may have been a shortfall in the trend used in the previous year’s projected claims. The reviewer could use the categorizations in HUER to review trends in the major service categories and identify cost drivers. In this example, if the large increase was caused by outpatient services, further drill-down is available in HUER to determine whether the increase was driven by utilization or cost in surgery, radiology, lab, emergency room, etc. Then it might be possible to assess whether the increase was due to a one-time event that is not likely to repeat, or if the increase is likely to impact future trend and carry forward to the rating period.” Supra note 31, at 7. 
41 Love et al., *All-Payer Claims Databases: State Initiatives to Improve Health Care Transparency.*
42 The Vermont Department of Banking, Insurance, Securities and Health Care contracted with Onpoint Health Data, and its subcontractor, Compass Health Analytics, Inc. for this purpose.
43 Supra note 31.
These system improvements appear to be under consideration in Vermont and are potentially accomplished through the addition of a “rate filing identifier” to link VHCURES submissions with their corresponding rate filing. Once linked, the carrier claims data driving rate filings can be evaluated against comparable data fields accessible to the Department's actuaries through the Vermont APCD. New Jersey may benefit from similar applications of APCD data and might also take advantage of suggestions from mature APCDs accrued during their first years of implementation.

**Risk Adjustment:** In addition, the ACA requires states to implement risk adjustment mechanisms to ensure plans compete based on quality and efficiency rather than the ability of insurers to attract “good risks.” HHS will implement risk adjustment mechanisms in states that do not implement their own. In a recent final rule, HHS addressed state-level claims data collection efforts necessary to support risk adjustment mechanisms required under the ACA. HHS clarified that states may use APCD claims data for risk adjustment purposes but in so doing, must comply with the requirements established by the rule. At the same time, the final rule explicitly grants states flexibility to choose the risk adjustment data collection that best suits their state.

Although the federally administered risk adjustment program will use a distributed model in which carriers retain control over individual level data rather than relinquish control to the database administrator, states that opt to operate their own risk adjustment mechanism may still require carriers to submit claims and other detailed data. Such data may assist states seeking to verify risk scoring by carriers and to prevent fraud in the risk adjustment process. The final rule also states “we believe that States administering a risk adjustment program should, to the extent possible, seek efficiencies in data collection across programs.” The Massachusetts Connector, for example, recently applied for access to Massachusetts APCD data in order to comply with the risk adjustment requirements of the ACA.

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44 Supra note 31.
48 Supra note 45.
**Provider Markets:** Because health care costs drive health insurance premiums, health claims data is required for complete analysis of insurance rates. Indeed the widespread unavailability of health cost information is suggested to be a more significant factor in health care price disparities than either case complexity or quality variability.\(^{50}\) Price obscurity is also suspected to provide market advantages to carriers and providers. The reaction of providers to transparency initiatives is unknown, but there is evidence to suggest providers may raise prices in response to mandated disclosure of negotiated rates.\(^{51}\) To avoid such unintended consequences and to maximize APCD potential, decisions regarding the type and context of price information disclosed should consider potential impacts on provider markets.\(^{52}\)

**D. Better Information for Policymakers**

Policymakers need comprehensive, credible data in order to design sound policy and allocate resources efficiently. For policymakers, APCD data can support critical health care expenditure analyses, reveal statewide trends and variations, and serve as the basis on which cost containment and payment reform initiatives are designed.

States with mature APCDs already use APCD data to advance policy. New Hampshire used APCD data to compare rates of coronary artery disease between Medicaid and commercial plan enrollees—information useful to tailor benefit design and allocate scarce resource according to population need.\(^{53}\) In 2011, Kansas used data from its APCD to develop cost containment strategies in Medicaid and for its state employee health plan. APCDs can also identify disparities in care and spending by region or community and establish a basis on which to reward provider efficiency. For example, the New Hampshire Insurance Department conducted a study of commercial claims for ground ambulance services. The study examined previously unknown utilization rates as well as charged and allowed amounts for emergency and non-emergency ambulance transport by carrier and by county.\(^{54}\)

APCDs can also provide data to better understand high cost cases, likely of interest to New Jersey in light of the Medicaid accountable care organization demonstration project. In

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\(^{52}\) Massachusetts Hospital Association, *Massachusetts Payment Reform: The Role of a Robust Massachusetts All-Payer Claims Database; Recommendations for Policymakers* (October 2011), http://www.mhalink.org/AM/Template.cfm?Section=Newsroom&Template=/CM/ContentDisplay.cfm&ContentID=17268.

\(^{53}\) Love et al., *All-Payer Claims Databases: State Initiatives to Improve Health Care Transparency.*

addition, APCDs may help identify the extent to which New Jerseyans leave the state (e.g., to
New York City or Philadelphia) for health care services—data useful for supply-side health system planning.\textsuperscript{55} APCD data may also prove useful in the future to identify fraud and abuse in the health care system.

APCDs can enhance the value of data collection initiatives already established in the state. Current databases, such as hospital discharge databases (HDDs), while important, leave critical gaps in health spending information. Payments to facilities and data from ambulatory care and pharmacy services tend to be absent from such datasets.\textsuperscript{56} APCDs can complement existing databases to provide more complete data to policymakers and enhance the value of previous state investments in health data.\textsuperscript{57}

Individuals, payers, providers, and policymakers may each find aspects of APCD data useful, though resistance to APCD development is noted from select stakeholders in other states. Providers may oppose public access to payment data, especially for outlier payments where case complexity may be unacknowledged. Payers may also object to release of claims data if it is perceived as proprietary information with strategic significance. To the extent payers stringently oppose centralized national data collection, state-operated APCDs may be preferable to federal initiatives.\textsuperscript{58} Others cite confidentiality concerns as their primary basis for opposition to APCDs.

\section*{IV. APCD Developments Nationwide}

Multiple claims database initiatives have emerged across the United States in recent years. These database initiatives may be at the direction of legislation or an order to an agency but can also be voluntarily constructed by private or government entities. At the federal level, for example, a 2006 federal executive order to “promote quality and efficiency in federal health care programs” required federally-sponsored health plans to make health service pricing information available to enrollees. Federal agencies including the Department of Health and Human Services (HHS), the Centers for Medicare & Medicaid Services (CMS), the Agency for Healthcare Research and Quality (AHRQ), and the Office of Personnel Management (OPM) are involved in efforts related to price transparency in health care.\textsuperscript{59}

A separate multi-payer claims database (MPCD) effort using public and private health plan data is under development by HHS in order to perform comparative effectiveness

\begin{thebibliography}{9}
\bibitem{55} Love et al., \textit{All-Payer Claims Databases: State Initiatives to Improve Health Care Transparency}.
\bibitem{56} Ibid.
\bibitem{57} Love and Steiner, \textit{Key State Health Care Databases for Improving Health Care Delivery}.
\end{thebibliography}
This large scale MPCD effort is funded by $1.1 billion of federal American Recovery and Reinvestment (ARRA) funds, $400M of which has been allocated to HHS. The federal MPCD seeks nationally representative data to provide longitudinal insights and contemplates synchronization with state APCDs. In addition, OPM announced creation of the Federal Health Claims Data Warehouse in 2010 in an effort to collect and analyze health claims data from the Federal Employees Health Benefits Plan.61

Private initiatives directed by payers also provide claims data for select uses. For example, the Health Care Cost Institute (HCCI) generates reports and makes data available to health service researchers from voluntary data contributions by four of the nation’s largest health insurers. Another claims data effort is administered by FAIR Health, a not-for-profit organization formed as a result of the New York State Attorney General’s investigation and settlement into formulas used by payers to calculate out-of-network reimbursement. FAIR Health gathers national data from payers to provide transparent cost information to consumers and health service researchers. Several other efforts gather and analyze health care claims data; other initiatives such as the Health Care Blue Book aim to provide health service pricing data to individuals.62

As state-directed APCDs reach maturity, their experience may offer insight into the challenges, legislative processes and stakeholder engagement associated with APCD development. Although no two states are exactly alike, some common elements emerge on the path to APCD establishment. Notably, Maine, New Hampshire and Vermont have common data elements and platforms that allow for multi-state regional evaluation. These three states collaborated to release the first “Tri-State Variation in Health Services Utilization & Expenditures in Northern New England”63 in 2010. This section briefly describes the experiences of five states: Maine, New Hampshire, Connecticut, Massachusetts and Utah.


In 2001, Maine created the first state-operated APCD. Maine’s APCD is administered by the Maine Health Data Organization (MHDO), which was established in 1996 as an independent executive agency dedicated to the collection of hospital inpatient, outpatient and financial data. Notably, in 2004, after an ERISA preemption challenge by a third party administrator (TPA) arguing claims data were plan assets and therefore TPAs were exempt from reporting requirements, a federal court ruled that the TPA must provide claims data to the APCD.65

Maine uses standard formats to collect: paid medical, dental, pharmacy claims files for all covered services provided to Maine residents who are both publicly (Medicaid and Medicare Parts A, B, C, and D) and privately insured; eligibility and membership files; health provider files; procedure and taxonomy code files.66 Maine’s claims data is used by the state to produce, among other things, the Maine HealthCost website which provides reports of health facility and practitioner payments for services rendered to Maine residents. Using the HealthCost website, individual health care consumers can access information regarding costs of specific procedures including arthroscopic knee surgery, colonoscopy, abdominal CT, MRIs and hernia repairs among others.67 Cost data can be sorted by procedure to view average statewide costs or by provider to view variation among practitioners.

NEW HAMPSHIRE

New Hampshire began collection of claims data in 2005.68 The New Hampshire Comprehensive Health Care Information System (CHIS) was created by statute in order to make health data “available as a resource for insurers, employers, providers, purchasers of health care, and state agencies to continuously review health care utilization, expenditures, and performance in New Hampshire and to enhance the ability of New Hampshire consumers and employers to make informed and cost-effective health care choices.”69 Under the statute, the New Hampshire Departments of Health and Insurance have joint responsibility for administration of the claims database, and health insurance carriers in the state must submit encrypted claims data. New Hampshire currently contracts with Milliman to collect and analyze claims data submitted through the APCD.70 The state also uses claims data from both commercial and Medicaid payers

64 See Alan M. Prysunka, Brief History of Maine All Provider-All Payer Claims Database, Maine Health Data Organization (June 2010), http://www.academyhealth.org/files/2010/tuesday/prysunka.pdf.
66 Prysunka, Brief History of Maine All Provider-All Payer Claims Database.
67 Ibid.
68 Patrick Miller et al., All-Payer Claims Databases: An Overview for Policymakers.
to produce a vast array of reports and studies on enrollment, utilization and disease patterns, in addition to consumer information web platforms. The New Hampshire Institute for Health Policy and Practice at the University of New Hampshire convened and coordinates the APCD Council with the National Association of Health Data Organizations.

**MASSACHUSETTS**

In Massachusetts, the APCD planning phase began in August 2008 and spanned approximately two years. In May of 2011, the Massachusetts APCD began receiving retroactive claims data dating back to 2008. The authority to mandate claims data submissions was conferred by a previous bill that established The Health Care Quality and Cost Council in Massachusetts. Massachusetts engaged stakeholders in a collaborative process led by the Division of Health Care Finance and Policy (DHCFP); drafted and adopted final regulations to govern the APCD; and developed specifications for a technical claims collection platform to align with other New England states to allow for regional comparison and ease burdens on multi-state carriers.\(^{71}\) During the planning stage, Massachusetts also applied to include Medicare data and solicited feedback from government agencies to ensure other data needs could be met by the new APCD.

The APCD implementation phase began in Massachusetts in August of 2010 and is currently ongoing. During this period, Massachusetts built a claims data collection system with encryption and audit capabilities and included software to analyze episodes of care. In 2011, DHCFP began holding daily technical advisory calls to address concerns with data submission and implementation and later hosted public forums on data governance issues. Massachusetts also partnered with the APCD Council and actively participates in data standardization efforts led by X12 and NCPDP discussed below.\(^{72}\) Payers in Massachusetts submit data on a monthly basis and APCD data is made available to other state agencies in Massachusetts.

Among other things, Massachusetts’ APCD data is currently used to support a consumer cost and quality assessment tool (“My Health Care Options”\(^ {73}\)), cost analysis and administrative simplification.\(^ {74}\) Recent discussions of payment reform in Massachusetts have brought additional public focus on APCD data and data collection practices.\(^ {75}\) In addition, analysis of health care cost containment initiatives by providers suggests that APCD data could be made


\(^{72}\) Supra note 71.


\(^{74}\) Supra note 71.

\(^{75}\) Massachusetts Attorney General Martha Coakley, *Examination of Health Care Cost Trends and Cost Drivers.*
more useful and/or accessible to non-governmental entities.\textsuperscript{76}

**CONNECTICUT**

Connecticut’s formal process to evaluate and make recommendations regarding multi-payer database development began in mid-2011 with the formation of a multi-stakeholder advisory group that ultimately recommended APCD-enabling legislation. In June of 2012, Connecticut’s governor signed legislation to establish a state-wide APCD.

The Connecticut Office of Health Reform and Innovation (OHRI) oversees Connecticut’s activities related to implementation of federal health reform.\textsuperscript{77} The APCD-enabling legislation delegates primary responsibility for planning, administration and implementation of the APCD to OHRI, but regulations are to be drafted in consultation with the Connecticut Office of Policy and Management. The Connecticut legislation requires the APCD to be funded using federal or private funds but prohibits the use of state funds for the APCD.\textsuperscript{78} Connecticut seeks funding for its APCD through the Level II Exchange Planning Grants administered by the US Department of Health and Human Services under the Affordable Care Act.

The Connecticut legislation specifies fines of $1,000/day for non-compliance with APCD reporting requirements; strict adherence to federal data privacy rules; and the ability to charge for data access and contract with outside vendors for assistance with APCD functions. Other key features of APCD operations including final decisions regarding which payers will be required to report data will be determined by regulation. Connecticut is currently engaged in early stages of the regulatory process and plans to seek the services of outside vendors for assistance with APCD development. The Connecticut APCD Advisory Group comprised of stakeholders will maintain a role in APCD efforts.\textsuperscript{79}

**UTAH**

The Utah APCD, administered by the Utah Department of Health’s Office of Healthcare Statistics, began collecting claims in 2009. The Utah APCD project began in 2007 with the passage of legislation requiring creation of an advisory group to study the potential of an APCD to assist in health data analysis within the state.\textsuperscript{80} Over nine months, a diverse stakeholder group created a draft plan for an APCD in Utah. That plan considered the need and utility of an

\textsuperscript{76} Massachusetts Hospital Association, \textit{Massachusetts Payment Reform: The Role of a Robust Massachusetts All-Payer Claims Database; Recommendations for Policymakers}.


APCD in Utah along with technical questions regarding how it would be built and used and by whom. After approval of the draft plan, the Utah legislature appropriated $615,000 annually in order to finance the APCD. Notably, the APCD appropriation bill passed the Utah legislature with bi-partisan support. In addition to the state appropriation from its general fund, Utah finances its APCD with annual $185,000 in Medicaid matching funds.

Although precise costs to carriers for APCD compliance in Utah are undocumented, the Utah Department of Administrative Services noted that the Office of Health Care Statistics “opened dialogue with payers in August 2008 about the Utah APD. The submission format and guidelines were developed with this dialogue and payer input in mind. The OHCS has accommodated the payers wherever possible to minimize financial and procedural impact. The APD architecture and data submission pathways were significantly altered to help reduce impact on the payers.”

Despite some resistance, the Utah APCD ultimately received support from legislators across the political spectrum. An initial legislative effort to establish an APCD at a cost of $1.2M failed in 2006, but one year later, legislation to plan an APCD without funding requirements passed and the process began. Some suggest legislative support flowed from the fact that the Utah legislature first charged the Utah Health Data Committee (located within the OHCS at the Utah Department of Health) with performing “episode of care” analysis. This type of analysis uses claims data, to evaluate the course and costs of care from initial diagnosis through the end of treatment or follow-up. OHCS communicated to the legislature that in order to perform such analysis, critical data regarding health care claims and costs must be gathered first and that data must be maintained on an identifiable basis in order to link claims across a continuum of care. Similar considerations of de-identified versus identified data should be considered by New Jersey at the appropriate time.

In order to allay privacy concerns, the Utah OHCS implemented what they refer to as the “highest encryption protocol there is available” and directly addressed data security issues in early development phases. Specifically, the Utah APCD set out to establish a set of claims data sufficient to answer questions regarding health care costs within the state, including “What happened?; When and where did it happen?; How much did it cost?; Who paid for what

83 Supra note 81.
85 Utah Department of Health, Utah Health Status Update: The Utah All Payer Database.
86 Ibid.
(including healthcare consumer out of pocket costs)?; What costs were not covered?; What other influences impact outcome (disease burden, comorbidities, demographics, environmental issues, access to specialists, etc.)?; What impact does preventive care, or lack thereof, have on outcome?; Were relevant standards of care met?" 88 The Utah database now contains more than 65 million claims dating back to 2007.

The Utah APD has, however, recently encountered significant setbacks. In August 2012, the company Utah hired to mine data went out of business thereby halting delivery of promised reports. Critics within Utah maintain that more funding is needed to support a fully functional APD, but the state recently moved forward with a request for proposals to hire a new APCD vendor. 89

V. APCD Design Considerations

APCD establishment requires consideration of multiple design elements that support both technological and analytic goals. Key considerations for APCDs include architectural structure; location and authority within government infrastructure; technological issues including data control and access; and funding. Although authority for many APCD functions may be created in legislation, the specific features of administration are more frequently delineated in regulation. This section reviews select design elements to highlight the scope of deliberations implicit in APCD establishment.

Basic APCD Architecture

An assessment of state laws and agency structures can help identify the best state-specific structure for governance and funding of an APCD. States may, for example, structure an APCD as part of a public/private partnership, within an existing state agency or as part of an interagency partnership, or locate an APCD within a state university. The majority of APCDs are managed by state agencies with legislatively granted authority to collect and disseminate APCD data. 90 For states that opt to locate an APCD within a state agency, most appear to prefer a health department or related entity 91 as opposed to an insurance department 92 or an interagency partnership. 93

88 Supra note 85.
90 Love et al., All-Payer Claims Databases: State Initiatives to Improve Health Care Transparency.
91 KS, ME, MD, MA, MN, OR, TN, UT.
92 In Vermont, APCD administration is performed by the Insurance Department.
93 In New Hampshire, administrative functions are performed through interagency partnerships with shared responsibilities defined by Memorandum of Understanding.
APCD tasks can be performed exclusively by APCD staff; by outside vendors engaged under contract; or by shared arrangement between the APCD and an outside vendor. A significant number of vendors are engaged in APCD-related tasks including implementation consulting; data aggregation and warehouse management; data analytics and the provision of data tools. APCDs typically collect data from commercial and Medicaid entities on a monthly basis. APCDs can be required to submit an annual report to the governor or legislature as specified in enabling legislation. A governing board or advisory committee directs the mission and operation of the APCD. Members can include directors of relevant state agencies and representatives of key stakeholders such as employers; physicians; consumers; payers; hospitals and other providers.

The operation and function of an APCD depends on its organizational model. APCDs may be organized using either a centralized or distributed approach. In a centralized model, the approach currently used by most states, payers submit data to the APCD or its designee after which all data and access is centralized. Under a distributed model, payers retain custody and control of data and make only de-identified claims and other data accessible to the APCD.

**Data Elements: Collection and Standardization**

In general, APCDs include data regarding providers, payers, patients, services and claims. Through rulemaking, states establish the data elements carriers are required to submit to the APCD. States appear to favor regulatory mechanisms over legislation to preserve the ability to modify data parameters without requiring additional legislative action. The state, or its designee, in turn manages the collection and analysis of these data elements according to its own specifications. As described in greater detail below, the data elements a state collects vary depending on the analytic functions the data will serve and other state preferences including privacy and efficiency.

**Data Included in APCDs**

The smallest unit of information gathered by an APCD is known as a “data element.” Data elements related to health services can include a full range of data for both primary and specialty care provided on inpatient and outpatient bases. Such data may include date of

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95 Geiger, “Decentralizing the Analysis of Health Data.”
96 This model preferred by some who critique large-scale data aggregation by government entities (e.g., American Civil Liberties Union, Center for Democracy and Technology) See Geiger, “Decentralizing the Analysis of Health Data.”
97 Comprehensive review of all data collection options are outside the scope of this Brief.
service; diagnosis and procedure code; lab tests; dental services and pharmacy data. Claim information relevant to APCDs includes charges, allowable amounts, payments; premiums and patient liabilities. For data collection purposes, payers may be identified by plan type but providers may be identified individually, by practice group or by hospital. Patient data may include demographic information such as gender; birthdate; and ZIP code. Patients may be identified directly but access strictly controlled or patient data may be encrypted (de-identified) which requires standardization across payers to make data sets compatible.

**Data Standardization**

Over time, state APCDs have created a nationwide patchwork of data elements and data collection practices. Nationally standardized data collection formats, however, appear a better way to allow for data comparisons across multiple markets and to ease burdens associated with APCD compliance for carriers, as well as to simplify management and analysis for APCD operators. Since 2008, the APCD Council has led efforts toward national standardization of data platforms for APCDs. The APCD Council is a federation of government, private, non-profit, and academic organizations focused on development and implementation of APCDs at the state level. It also provides technical assistance to help states establish both standard and custom APCD parameters.

Data collection appears most streamlined and cost effective when the required data elements are those that carriers normally seek in the course of their business operations. In addition, some recommend that the data elements and value sets used by APCDs should be adopted from “existing and accepted data standards.” In its engagement with industry stakeholders, the APCD Council found that payers request approximately nine months to make system changes required for initial APCD implementation and suggest limiting changes in APCD compliance to once per year with six months advance notice. In an effort to establish standard practices, the APCD Council has engaged two data standards management organizations responsible for maintaining industry standards for insurance claims and eligibility files for both medical and prescription coverage: ANSI X12N (“X12”) and the National Council

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100 APCD Council offers assistance to states seeking to establish an APCD, http://apcdcouncil.org/.
102 Ibid.
A Core Set of Data Elements

The federal Agency for Healthcare Research and Quality (AHRQ) provided support for the APCD Council to establish a technical advisory panel that included industry stakeholders to draft a set of core data elements for APCDs. The goal of the core data element initiative is to “harmonize” data collection across states. In October 2011, the APCD Council proposed a preliminary core set of elements for reporting medical data; a subsequent proposal addresses eligibility data. The draft list is based on an inventory and edit of common data elements used by Maine, New Hampshire, Vermont, Minnesota, Tennessee and Massachusetts. In total, the APCD proposed core set of approximately 100 core data elements for both medical and eligibility data submission. A selection of data elements from the core lists includes:

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103 APCD Council, History of APCD Council Harmonization Efforts.
104 Ibid.
The APCD Council has engaged the two data management standards organizations described above to ensure standards are developed in lockstep with other initiatives. In addition, the United States Health Information Knowledgebase (USHIK) keeps a complete inventory of 188 data elements collected by selected states (Maine, Maryland, Minnesota, Massachusetts, New Hampshire, Oregon, Tennessee and Vermont). 108 USHIK has generated a metadata registry to allow comparisons of standards across these states and presumably will add other states over time. 109 The Health Care Cost Institute, a private initiative discussed above with participation from four major national carriers, also collects cost data in a smaller proportion than the state-mandated databases.

**Data Linkage to Multiple Sources**

APCD Databases may be flat or complex in structure- flat databases only include claims profiles; complex databases link claims to individualized and system data to generate potentially highly useful profile-based data. In addition, states have the option to gather retrospective data

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107 Concerns regarding data privacy, confidentiality and encryption are discussed below.


109 Ibid.
through the APCD to support longitudinal analysis.\textsuperscript{110} Other potentially complementary data sources that help create a robust picture of statewide health costs include hospital discharge and charity care claims data sets.\textsuperscript{111} Electronic medical record (EMR) initiatives, health information exchanges, disease registries and federal databases among others are also potential APCD collaborators depending on preferred APCD functionality. Despite efforts toward national standardization, the parameters and extent of data required for APCD submission can still vary and depend on state-specific design considerations. APCD development should consider the extent to which multi-source data interface is desirable.

\textbf{Data Excluded from APCDs}\textsuperscript{112}

States may seek to exclude certain data from APCDs. In addition to encryption-based protection, patient data collected by the APCD may, for example, exclude direct identifiers such as names, addresses and Social Security Numbers.\textsuperscript{113} Certain clinical data may be excluded. Premium and plan benefit information may be segregated or collected by other entities and potentially linked to APCD data. For example, New Hampshire uses premium information in order to form a “benefit index” to relate premiums to claims.\textsuperscript{114} Some combinations of medical loss ratio (MLR) data; data regarding denied claims; pre-paid health plans; uninsured, self-pay and workers compensation populations have also been excluded from APCDs. Although payments to providers are within the scope of an APCD, non-claims based fiscal transfers such as capitation and incentive or rebate payments from insurers to providers, when excluded from APCDs, can result in underestimation.\textsuperscript{115} The extent to which such categorical data exclusions limit the utility of APCDs is outside the scope of this Brief.

\textbf{Monitoring and Compliance}

APCDs also serve monitoring, compliance and enforcement functions. Delay or non-compliance with APCD data submission requirements may subject payers to financial penalty. For example, payers in Massachusetts face penalties of $1000 per week of delay; in Oregon penalties are $500 per day and in Tennessee payers incur a $100 per day fine.\textsuperscript{116} APCDs themselves must also comply with applicable federal and state data requirements.

\textsuperscript{110} Love and Sullivan, \textit{Cost and Funding Considerations for a Statewide All-Payer Claims Database (APCD)}. \\
\textsuperscript{111} Love and Steiner, \textit{Key State Health Care Databases for Improving Health Care Delivery}. \\
\textsuperscript{112} Porter, \textit{Fact Sheet: APCD and Health Reform}. \\
\textsuperscript{113} Park, \textit{Allowing Insurers to Withhold Data on Enrollees’ Health Status Could Undermine Key Part of Health Reform: Data Collection Needed to Ensure Insurer Accountability and Reduce Risk of Error}. \\
\textsuperscript{114} National Conference of State Legislatures, “Collecting Health Data: All-Payer Claims Databases.” \\
\textsuperscript{116} National Conference of State Legislatures, “Collecting Health Data: All-Payer Claims Databases.”
**APCD Costs and Funding Sources**

Funding is required for both initial development and ongoing operation of an APCD. Specific cost projections depend on the number of data sources, desired functionality and design preferences. Although projections specific to New Jersey are premature, it may be useful to highlight cost and funding structures of existing APCDs in other states.

Costs associated with APCDs- for states and for payers required to submit data- are greatest during early development phases when infrastructures for collection, aggregation and analysis must be established. Sharing common collection standards across data gathering initiatives appears an effective way to reduce costs of APCD creation and participation.\(^{117}\) Ongoing costs for APCDs depend on the number and scope of data sources, the technological platforms of the APCD, and the format and function of data reports.

The National Association of Health Data Organizations (NAHDO) reviewed internal APCD costs and vendor contracts in ten states.\(^ {118}\) The proportion of APCD activities performed internally by state staff as compared to activities provided by outside vendors varies considerably across states. Internal duties vary and corresponding staffing estimates are not precise. The report indicates four categories of duties performed by internal staff: (1) rulemaking duties performed by internal staff are limited to the first year and include project management (0.5 FTE); legal resources (1.0 FTE) and technical resources (0.5 FTE); (2) state staff perform vendor acquisition and management functions in the first and subsequent years at a total of 0.75 FTE spread over two employees; (3) data policies and procedures are managed by 0.25 FTE in first and subsequent years and supported by 1.0 FTE of legal resources (the legal resources required drops to 0.1 FTE after the first year); (4) data management analysis and support accounts for 0.5 FTE for initial and maintenance years along with estimated $25,000 in IT infrastructure costs and highly variable software costs up to $275,000 for initial investment.\(^ {119}\)

The scope of services for which states engage outside vendors also varies considerably. The NAHDO report described vendor services in three main categories: data aggregation alone, data analytics alone and a combination of data aggregation and analytics. The average contract length reported was three years. States engage outside vendors for aggregation services contracts that generally include only collection of data from payers. States will then perform analytic functions internally or engage a separate vendor for analytic services. Data aggregation only contracts range from $202,000 to $896,000 with a median amount of $812,765. Seven states have single contracts for combined data collection and data analysis services. The analytic services performed under these contracts vary widely and the NAHDO report suggests

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\(^{117}\) Love and Sullivan, *Cost and Funding Considerations for a Statewide All-Payer Claims Database.*


\(^{119}\) Ibid.
that may account for the range of costs (from $462,000 to $1,000,000 with a median of $672,000). Finally, two states maintain contracts for analytic services independent of other functions and report a range of $244,000 to $1,500,000 for which service providers analyze data aggregated under other contracts. Total annual contract amounts range from $202,000 to $1,474,000 across states, median annual contracts vary between $672,000 and $856,000. Ultimately, it is difficult to put one price tag on the cost of an APCD, but the estimates described here illustrate the range of costs incurred for APCD development to this point.

States fund APCDs from a variety of sources including general appropriations (New Hampshire); fee assessments on carriers and facilities (Vermont); Medicaid matching funds (Utah); foundation support (Colorado) and, to a limited degree, sales of data generated by the APCD itself (Maine). As mentioned above, federal fiscal support is currently available to states through rate review and exchange establishment grant funds created by the Affordable Care Act and a number of states appear to be making use of these time-limited federal funding streams. Paid access to APCD data can also generate some, but seemingly not significant revenue. Because the value of an APCD accrues over time, long-term sustainability is essential. States may therefore consider multiple funding mechanisms to ensure viability.

Data Access and Privacy
Privacy and confidentiality are among the most complex and controversial concerns surrounding APCD development. The decision to collect identified as opposed to de-identified data rests on the desired functionality of the database along with privacy concerns inherent in data collection. Storage and technological capacity directly influence the agility and sophistication of an APCD. As a result, database design and access require careful consideration and monitoring to ensure both privacy and high returns on investments in claims data collection.

The extent of data access can also impact the cost of APCD operation and administration. Access to varying degrees of APCD data may be granted to some combination of: APCD staff; single or multiple government agencies; the public through APCD-issued reports; regional partners in neighboring states to harmonize data; researchers on either a free or fee-based system. Access to APCD data may be also governed in the future by a dedicated body such as a “Linkage Review Board” similar to the institutional review board model. Regardless of state variation in data collection practices, all data released by APCDs is de-identified.

Notably, the HHS rule mentioned above that addresses the use of APCD claims data to support risk adjustment mechanisms responds to comments on the proposed rule that focused

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120 Ibid.
121 Love and Sullivan, Cost and Funding Considerations for a Statewide All Payer Claims Database (APCD).
122 Miller, All-Payer Claims Databases 2.0: The Next Evolution.
on privacy concerns related to data collection. Because risk adjustment mechanisms will be operated at both federal and state levels, HHS set forth rules for both federal and state claims data collection for risk adjustment. Specifically, under the federal rule, states must limit their collection of personally identifiable information to that which is reasonably necessary to perform their risk adjustment methodology and requires states to implement security standards consistent with the HIPAA Security Rule. States are explicitly granted flexibility to design security requirements consistent with the HIPAA Rule, and also maintain the option to implement security requirements more strict than those set forth in HIPAA. Where the federal government will operate risk adjustment mechanisms on behalf of states, the final rule states that a distributed model in which carriers retain possession and control of claims data will be used.

VI. Discussion

APCDs have limitations but appear to be important tools to document health care costs and utilization to inform policymaking. To the extent states serve important functions in health insurance regulation, states may be uniquely positioned to lead APCD efforts. State knowledge of local markets and payers can foster stakeholder engagement, development of state-specific platforms and public-private partnerships through which data can be gathered.

Should New Jersey opt to pursue APCD development, several next steps are to be considered. A New Jersey APCD would likely require and benefit from multi-agency interface, thus early discussions should include possible partners. In addition, it may be useful to contemplate possible APCD interaction with existing databases and/or health information technology (HIT) efforts across the state. Depending on the course of federal health reform implementation in New Jersey, it may be efficient to establish an APCD simultaneously with a health insurance exchange. Indeed APCDs can also provide useful data on which to evaluate the impact of federal health reform on population health, costs and utilization.

Because potential data submitters may already collect and maintain data required by APCDs, stakeholder participation in APCD design can draw on experience within the state and minimize duplication. One approach to APCD planning suggests first conducting an inventory of commercial health insurance carriers to estimate enrollment, and then add public payers in order to project the scope of the APCD. Subsequent planning steps include decisions regarding governance and funding followed by design of technical platforms and analytic models.

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124 Ibid.
125 Denise Love and Alan Prysunka, All-Payer Claims Database (APCD) Technical Build Guidance Document (APCD Council, July 2011),
New Jersey may also look to states with mature mandatory APCDs for guidance. Model legislation, implementation plans, administrative details, and technological infrastructures used by states that have already established APCDs are available for reference. In addition, the APCD Council offers support for states considering APCD development. Federal funds allocated to states by the Affordable Care Act (ACA) to enhance premium rate review capacity or build exchanges may also be used to support APCD activity.

At a minimum, well-analyzed APCD data could deepen the conversation about health care costs in New Jersey. This Policy Brief sets out basic information about APCDs, highlights potential benefits to New Jersey of initiating APCD development and raises key questions for discussion should next steps be pursued.
