Achieving States' Goals for All-Payer Claims Databases

June 2018



KEY HIGHLIGHTS

- Many states are pursuing the use of all-payer claims databases (APCDs) as a way to improve the health-care delivery system through data transparency.
- However, challenges related to the collection and use of claims data—such as privacy concerns, use of proprietary data, and validity of the data collected—can impede states' ability to achieve their goals.
- By partnering with key stakeholders to implement recommendations that address these critical challenges, states can help APCDs realize their promise.



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APCDs in 15 states

accept data from Anthem, Inc. and its affiliated health plans

Overview

The growing interest among states to develop and implement All-Payer Claims Databases (APCDs), also sometimes referred to as Multi-Payer Claims Databases (MPCDs), presents valuable opportunities but also poses notable challenges.

Anthem, Inc. and its affiliated health plans submit data to APCDs in 15 states and have experience working with states in development and implementation of APCDs. In Anthem's experience, states have commendable goals for APCDs, including collecting critical information needed to make health policy decisions, to support healthcare and payment reform initiatives, and to address the need for transparency in healthcare. However, realization of these goals is hampered by a number of challenges that result in incomplete data collection (e.g., not all payers submit data), variation in state reporting requirements, and misalignment with other data collection programs and efforts.

In collaboration with our state partners, Anthem and other payers can help states to develop clearer guidelines for the overall purpose and specific goals of the APCDs, the use of the data, and the data collection processes. Strengthening partnerships between states and stakeholders through better collaboration can help support states' goals for APCDs.

This issue brief discusses key issues, both technical and policy related, that states should consider as they continue to implement and administer APCDs. This paper also discusses high-level recommendations that should guide the operation of APCDs to ensure the intended goals and objectives are achieved.



What is an APCD?

The APCD Council defines APCDs as "databases, typically created by state mandate, that generally include data derived from medical claims, pharmacy claims, eligibility files, provider (physician and facility) files, and dental claims from private and public payers."

Source: APCD Council. (2015, March). All-Payer Claims Database Development Manual: Establishing a Foundation for Health Care Transparency and Informed Decision Making. Retrieved November 17, 2017 from: www.apcdcouncil.org/manual

States rely on APCDs to collect comprehensive data

Many states across the country are establishing APCDs as a way to collect data from private and public payers and make it available to third parties for a variety of research and data transparency activities.

There is variation in states' use of APCDs. Some states mandated the formation of an APCD in state statute and require payers to submit data. In other states, no APCD was mandated in statute but interested third parties came together to establish one; in these states, both the APCD effort and data reporting are voluntary.

Updated data (excluding the District of Columbia) indicates that more than half of the states have some form of an APCD in place or have a strong interest in creating one (see Appendix A for more information on state activity).¹

Vision and Goals

Each APCD typically has a defined mission and set of goals. APCDs established through legislation have their mission and goals set forth in the enacting legislation. For APCDs that are formed through some other arrangement (e.g., executive order, partnership among third parties), the mission and goals for the APCD can be set forth in a statement of purpose, joint agreement, or other founding documentation. The goals of APCDs vary from state to state. Common objectives include filling critical gaps in information, generating actionable information for stakeholders, creating a more transparent healthcare system,² and generally achieving the three-part aim of increasing access to care, improving quality of care, and reducing the cost of care.

Some states establish very broad goals while other states are much more specific. For instance, the state of Maine's statement of purpose for its APCD is very broad, indicating that the purpose of the APCD is to "create and maintain a useful, objective, reliable, and comprehensive health information database that is used to improve the health of Maine citizens and issue reports."³ In contrast, Oregon delineates a very specific vision—codifying nine objectives for the use of data submitted to the APCD (e.g., evaluating health disparities related to race and ethnicity, comparing the efficacy of treatment settings and approaches, identifying demands for healthcare).⁴

While states' goals for their APCDs may vary, one commonality is that most states do not clearly define how any of these goals will be measured, nor do they identify use cases to determine if the data collected will aid the state in the achievement and measurement of the goals.



Common goals of APCDs include filling information gaps, generating information consumers can use, and increasing transparency.

Data Collection

APCDs collect an array of data across healthcare programs and plan types, although submission requirements can vary. Issuers may be required to submit data for plans they offer in the commercial market, including on the health insurance exchanges, as well as through the Medicare, Medicare supplement, and Medicaid programs. Payers report data to the state's APCD on a mandatory or voluntary basis, as applicable. The data reported is extensive, typically including: medical, dental, and pharmacy claims; information on the member, product, and provider; and, in some cases, premium data from the insurer.

The formats in which APCDs collect data vary by state and by health insurance program (e.g., standard 837 transaction form, the X12 form used to share encounter data between entities).⁵ Steps have been taken by the APCD Council to create a common data layout (CDL) but this has not been adopted by any state or APCD entity to date.

Use of Collected Data

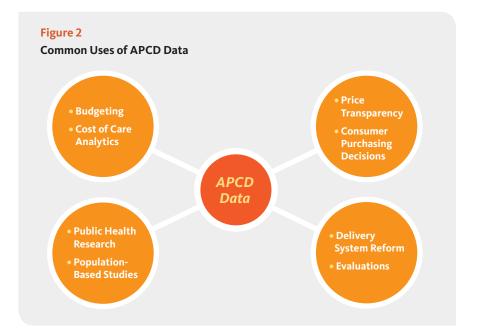
As with other aspects of APCDs, there is variation in how states use the data collected. Some states use the data to generate insights that address the APCDs' foundational purpose, such as analyzing costs, informing quality improvement initiatives, or looking into health disparities. States may also make the data available to third parties in de-identified or public use files, limited data sets, and/or identifiable data formats with appropriate data protections.⁶ Some states, like Massachusetts, use the APCD reporting as a replacement for much of their mandated reporting in the state. Still other states currently use very little of the APCD data they collect.



APCD data can be used for a variety of research and policy purposes

The basic purpose of APCDs is to serve as a platform for the collection, aggregation, sharing, and analysis of healthcare data from disparate sources.⁷ APCDs can be used to fill critical information gaps in order to make effective health policy decisions, support healthcare and payment reform initiatives, and increase transparency in healthcare.

In a healthcare delivery system that increasingly relies on data to improve access, quality, and cost of care, APCDs present an opportunity to make data more readily available to all stakeholders in the healthcare system to inform these research, policymaking, and purchasing activities. (See Appendix A for a snapshot of how states are using APCD data.)



Informing Employer and Consumer Purchasing Decisions

As a central repository for all healthcare related data (e.g., spending, utilization, member and provider information) across all payers within a given state, APCDs are a comprehensive resource. Researchers, consumers, employers, state policymakers and regulators, and others can access the data in order to make more informed decisions about quality and costs. For example, Maine's APCD uses a public-facing website and comparison tool to provide consumers and employers with information on costs, quality, and patient experience for medical care in the state.⁸ In Colorado, the state developed a website that uses data from the APCD to report on the cost and utilization of healthcare services by geographic area.⁹ Using APCDs as a resource to inform consumer, employer, and state purchasing decisions aligns with the movement towards more consumer-directed healthcare in both commercial and government health programs.



APCDs have the potential to enhance access to data that can lead to more informed decisions about quality and cost.

Informing Research, Policy Analysis, and State Budgeting Activities

The comprehensive data collected by the APCD can also be used by states, researchers, and other entities to better inform healthcare planning and policy decision making. Having access to data that covers all payers and all individuals enrolled in health insurance coverage provides a valuable opportunity to analyze trends in healthcare costs and utilization. For example, for states, this could mean analyzing Medicaid spending and utilization to support more-accurate annual or biennial budgeting as well as informing proposed changes to its Medicaid program. For researchers, access to this dataset can enhance their capacity to analyze churn between commercial and government health insurance programs or identify areas experiencing provider shortages, among other critical topics. Researchers and state agencies can also use APCD data to analyze and address population health issues, such as chronic disease, if claims and utilization data collected by APCDs can be linked with clinical data (e.g., lab results).

Informing Delivery System Reform and Evaluations

APCDs can also facilitate evaluation of delivery system reforms—especially those that span payers and providers—such as primary care health homes, payment reforms, or quality improvement initiatives. States and researchers can also use data collected by the APCD for population-based studies, such as studying the characteristics of high-cost populations or evaluating the differences in healthcare use among urban versus rural populations. States are already putting APCDs to use in some of these areas. For instance, in Vermont, the state used data from the APCD to develop primary care service areas for a spatial analysis study. In New Hampshire, the state uses APCD data for community health assessments.



SAMHSA regulations generally restrict sharing the data of individuals receiving SUD services or with a SUD diagnosis without their permission.

Current design and implementation of APCDs present significant challenges

While states establish APCDs with the goal of improving the healthcare delivery system, there are a number of challenges associated with the design and execution of APCDs that risk diminishing states' achievement of this objective. These issues also impact the success of the APCDs' role as a robust data repository. These challenges relate to consumer privacy issues, how and what data are collected, and anti-competitive concerns.

Privacy Issues

Privacy concerns are a key factor that limit the data that can be collected and shared by APCDs. This is particularly relevant with respect to the Substance Abuse and Mental Health Services Administration's (SAMHSA) regulations on the confidentiality of substance use disorder (SUD) patient records (42 CFR Part 2), commonly referred to as the "Part 2" regulations.¹⁰ These SAMHSA regulations generally prevent health plans and administrative service organizations (ASOs) from releasing covered records of individuals receiving SUD services or with a SUD diagnosis to an APCD without the express consent of the affected member or for other very limited permitted purposes. The restrictions that the Part 2 regulations place on data sharing may limit or even impede the research goals of APCDs.

The Part 2 regulations create complications for health plans and ASOs with respect to the data reporting requirements of APCDs. For example, before releasing SUD data to an APCD for Institutional Review Board (IRB) approved research, issuers need to know with certainty whether use of the data by the APCD is within the limited research exemption under Part 2 to avoid having to seek express consent from the affected patient.

Given that data reporting is mandatory in many states, and the Part 2 regulations do not include a "hold harmless" approach or federal safe harbor for sharing data with APCDs, issuers need to take additional steps to ensure appropriate use of the data; often, this requires manually redacting specific claims lines in provider and pharmacy files that indicate SUD treatment.¹¹ The process for redacting protected information from claims can lead to substantial delays in submitting data to the APCD and limits the utility of the data. Also of significant concern for payers is the potential for civil penalties, criminal penalties, or both for non-compliance with Part 2.

Part 2 privacy restrictions also create complications for an APCD in the event that it holds this regulated SUD data, as the regulations could limit the APCD's use of the data, including their ability to share the data with researchers and other third parties.¹² With SAMHSA having released final rules in January 2017 and 2018, APCDs are only beginning to work through the issues related to privacy and the sharing of data on individuals with SUD.¹³

Other privacy concerns exist with respect to sharing data with APCDs and the use of that data by the APCDs. For instance, if payers are mandated to report identifiable, raw claims data, as opposed to de-identified data, there is substantial added privacy risk since identifiable member information will be held by the APCD, as it is generally no longer protected by certain privacy rules—including the Health Insurance Portability and Accountability Act (HIPAA)—in the hands of the APCD. However, any inadvertent sharing of identifiable data with third-party groups would have serious implications for the payers and the APCD, such as civil and criminal penalties, as well as for the individuals whose personal information is shared (e.g., identity theft, violation of privacy rights) if it is found information was not properly shared.

If the data collected by APCDs includes identifiable information, the inability to share the data with third parties can interfere with the APCD achieving its goals and limit its value overall. Steps should be taken by APCDs to use third-party vendors to enable the de-identification of the data prior to submission by the data suppliers. Methods exist to allow the data suppliers and users to match data about individuals without identifying them, thereby allowing the APCD to store this data in a de-identified manner and still preserve the utility of the data for research.

Exclusion of Data from ERISA Plans

One of the beneficial features of an APCD is its function as a comprehensive data repository. Having data across all payers and for all members enrolled in health insurance coverage creates a robust data set from which transparency and informed decision-making can flow. However, gaps in data diminish the utility of the APCD. Recent legal and regulatory decisions limit the data that can be collected by states; this may impact the state's goals and may limit the value of APCDs.

In particular, a recent decision by the United States Supreme Court in *Gobeille v. Liberty Mutual Ins. Co.* dealt a blow to the comprehensive nature of APCDs.¹⁴ The central issue of the case was Vermont's requirement that all issuers report data to the state's APCD. The Court ruled that the Employee Retirement Income Security Act of 1974 (ERISA) pre-empts state APCD laws when the state mandates collection of ERISA plan data. The decision by the Supreme Court means that ERISA plans cannot be required to submit data, but may opt in voluntarily to the extent permitted by HIPAA. However, stakeholders—such as health plans, legal experts, and even state policymakers —have differing interpretations of whether both self-insured *and* fully insured ERISA plan data are covered by the ruling or only self-insured ERISA plan data. The extent to which the *Gobeille* decision created gaps in the data submitted to APCDs diminished the APCDs' effectiveness as a resource.



The Supreme Court's Gobeille decision creates gaps in data submissions that diminish the role of APCDs as a comprehensive resource.



APCDs are collecting information from payers that can have anti-competitive implications for plans.

Anti-Competitive Concerns

APCDs are collecting information from payers that can have anti-competitive implications for plans. For instance, as noted earlier, APCDs mandate that payers submit raw claims data, instead of de-identified data. In addition to the privacy issues discussed previously, the submission of raw data also raises anti-competitive concerns because it includes the negotiated rates between payers and providers.

Making this information available to third parties through APCDs can have a negative impact on payers' ability to negotiate competitive, actuarially sound rates with providers. In fact, the Federal Trade Commission (FTC) has weighed in on this area of concern and issued opinions suggesting it could present a substantial risk of reducing competition while providing little benefit to the consumer.¹⁵ Additionally, the FTC noted that disclosing health plan pricing and cost information could lead to providers coordinating on prices—agreeing on what they will offer to plans in advance instead of competing with each other to offer the best price.^{16, 17}

These concerns are compounded by permitted uses of the APCD data. In at least one state, the APCD allows third parties to access the data without a specific research plan for using the data. Furthermore, that particular state, along with others, worked with vendors to hold seminars for providers and hospital systems to demonstrate how they could benefit by using the APCD data in their rate negotiations with health plans. This type of practice directly interferes with a payer's ability to protect its confidential and proprietary data (e.g., discounts, savings, and allowed amounts). Using APCD data for this type of activity can have negative consequences for the delivery system. Consequently, it is important that access to and use of APCD data is not open-ended; any use of data beyond the APCD's specified goals should be prohibited, unless approved by the APCD's governance group on a case-by-case basis.

Data Standardizaton

Currently, there is no standard approach for collecting and reporting data to APCDs. In general, each state has its own unique reporting and submission requirements. Yet there are potential benefits to standardization. For example, a standard reporting format could reduce the variability in the types and formats of data requested across states and better align APCD data collection and submissions with those of other federal and state programs. Standard data reporting could also support the use of APCD data for research beyond state lines, since data contained in other state APCDs would be the same information in the same format.

The National Association of Health Data Organizations (NAHDO) has led one effort to standardize reporting through the creation of the Common Data Layout (CDL). The goal of the CDL is twofold: first, NAHDO hoped that the Department of Labor (DOL) would use the CDL for its annual

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Variation in state submission requirements can hinder research across states and alignment with federal programs.



Most APCDs lack processes to verify the quality and accuracy of data before releasing it for external use. reporting process that captures the ERISA data lost as a result of the *Gobeille* decision.^{18, 19} Second, the CDL was intended to simplify and create consistency in reporting and remove the burden cited in the *Gobeille* decision regarding each state's unique reporting requirements.²⁰

However, in its current format, the CDL is unlikely to address key issues with data standardization. First, the CDL was not developed by a standardsetting organization, but by a mostly state-funded group. As such, the CDL reflects the perspective of only one stakeholder group (vendors) besides states. Broader perspective needs to be incorporated to ensure any proposed approach reflects the input of multiple stakeholder groups. Second, there are concerns that adoption of the CDL could have unintended consequences if it allowed third parties to more easily combine data across states and programs without any validation of the data and methods of aggregation. Finally, the CDL would have only a marginal effect on reducing administrative burden. The effort should move beyond standardization of data elements alone and also impose definitional standards, standardization of data edits, and data quality standards.

While there are benefits to standardization, there appears to be little appetite at the federal and state levels to adopt the CDL. A few states have considered the CDL but no state has announced the adoption of the CDL as part of its data submission guide (DSG) updates for 2018.²¹ As of June 2017, a final draft of the CDL was in development.²²

Data Submission Issues

Payers face technical and timing challenges when it comes to submitting data to APCDs. For instance, the timeline for data submissions is usually less than 120 days (four months), which is difficult for most payers to achieve. Most payers have indicated they need six months to set up a new APCD submission and at least four months to process state updates to the data submission guide for data extract submissions.²³ Submissions can be further complicated by the specific data requirements of the APCD. For instance, one state is considering requiring payers to submit the premium amount at the member level, which payers typically do not track. Reporting this data will require payers to create a new algorithm to generate this information.²⁴

In addition, most APCDs do not have a data verification process in place to validate that the data they've collected and processed, which sometimes includes aggregating raw data into episodes or otherwise synthesizing for end users, is ultimately accurate. Anthem's experience in some states revealed that states are not familiar enough with the APCD collection processes to create an oversight and validation process. As a result, it is likely that submitted data is not being properly verified before being released to external parties. Anthem has had the opportunity to validate data in several of our markets. In one state, we identified errors caused by the vendor's incorrect handling of the APCD data. The process for correcting those issues can be extensive and time consuming, requiring more than two years of working with the state and APCD vendor to correct the issue and then verify the correction. Nevertheless, this experience underscores the importance of a data verification process.

Beyond problems related to data verification and the timing of submission, issuers can also encounter technical challenges when it comes to submitting data captured under certain types of provider contracts. In particular, value-based payment arrangements or other contracting mechanisms that do not rely on fee-for-service (FFS) payments add a level of complexity for data submission. Since issuers do not pay FFS, the only option they have is to calculate a FFS-equivalent rate in order meet the data submission requirements of APCDs. This is not the most accurate way to report data reflective of value-based contracts and can complicate the timely submission of data to APCDs.

Stakeholders can implement changes that help APCDs achieve their promise

Currently, Anthem collects and submits data to APCDs in 15 states, and also has assisted some of our state partners with data verification activities. Based on this experience, we offer the following recommendations to help address the challenges discussed in this paper and ensure APCDs achieve their goals.

1. APCDs should have a clear purpose and mission.

States should have a clear understanding of what they want to accomplish with an APCD and then define the scope of the APCD in accordance with those goals. The purpose and mission should be supported with specific use cases that are demonstrably effective and can be used to measure progress and achievement of the defined goals.

2. APCDs should be financially stable for the long term.

A mature long-term stability plan is critical, as federal grants and user fees alone cannot adequately support the effort into the future. States should not sell health plan data to third parties.

3. APCDs should have realistic implementation and collection timelines.

It is critical that states regularly collaborate with stakeholders to develop realistic timelines for implementation and submission requirements.

4. APCDs should establish consistent data collection standards.

APCDs are not aligned or harmonized with data submission requirements for other programs (e.g., quality measurement and reporting, value-based payment models, risk adjustment models). States should model data collection standards after other existing state efforts.

5. Data collected should be legally accessed and meaningful.

The adoption of any reporting processes for use and disclosure of protected health information (PHI) must be compliant with HIPAA and existing state privacy laws. States also should abide by the minimum necessary data standards, as defined under HIPAA, and collect only the minimum data required to support its objectives and accomplish the stated goals. To minimize risk to patient privacy, APCDs should use third-party vendors to de-identify the data while still preserving the use of the data for research via creation of a protected member identifier that allows for member tracking/matching across claims.

6. APCDs should have strong relationships with and input from payers and other stakeholders.

Payers should be partners in APCD efforts. Payers can help states understand which data elements are most and least relevant to the APCD's goals, how best to aggregate data among multiple payers, and the most meaningful uses for the data. This includes working with payers on how best to collect and use data reflective of value-based payment arrangements that do not rely on FFS rates. Payers should be represented on all governance groups that oversee state data use requests and the data use process. This ensures representation of payers' interests—such as with respect to use of proprietary financial information and that data are used only for purposes that support the APCD's specified goals. Finally, in recognition of the state-payer partnership, states should not impose penalties on insurers making a good-faith effort to complete and submit accurate data in a timely manner.

7. APCDs should adopt a decentralized approach to data collection and sharing.

A decentralized approach through a federated, or distributed, data model would allow stakeholders to realize the benefits of APCDs while minimizing the challenges faced by states, researchers, and issuers.²⁵ For instance, this approach would reduce infrastructure costs by eliminating the need to create, maintain, and secure centralized data warehouses. Additionally, a federated approach keeps proprietary and protected health information in the control of the issuer and also enables data holders to review and authorize data use requests on a case-by-case basis.²⁶



Addressing data limitations and providing important protections for consumers and health plans can help states achieve their goals for APCDs.

Conclusion

Although APCDs can have value, they also pose challenges related to data collection and use. These include privacy concerns, potential disclosure of proprietary data, unknown validity of the data collected, and third-party use of the data in a manner that violates the intended uses set forth by the APCD.

Efforts to advance healthcare outcomes would be better served by relying on partnerships with entities, such as plans and other payers, that maintain existing data environments and best understand how to navigate and use the data.

Nevertheless, states are increasingly looking to APCDs as a tool to improve healthcare delivery and information transparency. Before proceeding, states should clearly articulate the key goals and objectives for the APCD while being aware of data limitations that may jeopardize achievement of these goals. Further, given the extensive role that payers play in APCDs across multiple states, health plans can serve as valuable resources for states, vendors operating APCDs, and other stakeholders working towards improving the accuracy and value of the data collection and reporting processes. Finally, by adopting the recommendations included in this paper, states, in close partnership with key stakeholders, can better achieve their stated goals while balancing important protections for consumers and health plans.

Appendix A: Overview of States' All-Payer Claims Databases

State	APCD Data Submission	How States Are Using APCD Data ⁱ			
		Budgeting & Cost of Care Analysis	Price Transparency & Consumer Purchasing Decisions	Delivery System Reform & Evaluations	Public Health Research & Population-Based Studies
Arkansas [†] "	Mandatory	Х	Х		Х
California	Voluntary		Х		
Colorado [†]	Mandatory	Х	Х	Х	Х
Connecticut [†]	Mandatory	Х	Х		Х
Florida ^{†iv}	Mandatory	Х	Х		
Kansas ^{†iv}	Mandatory	Х	Х		Х
Maine [†]	Mandatory	Х	Х		Х
Maryland ^{†iv}	Mandatory	Х	Х	Х	Х
Massachusetts [†]	Mandatory	Х	Х	Х	Х
Michigan	Voluntary			Х	Х
Minnesota	Mandatory	Х	Х	Х	Х
New Hampshire [†]	Mandatory	Х	Х	Х	Х
New York [†]	Mandatory	Х	Х		Х
Oklahoma	Voluntary				Х
Oregon ^{†vi}	Mandatory	Х	Х	Х	Х
Rhode Island	Mandatory	Х	Х	Х	Х
South Carolina	Voluntary			Х	Х
Utah [†]	Mandatory	Х	Х		Х
Vermont [†]	Mandatory	Х	Х	Х	Х
Virginia [†]	Voluntary		Х		Х
Washington [†]	Mandatory	Х	Х	Х	Х
Wisconsin ^{vii}	Voluntary		Х		Х

Notes

Source: Information on state APCD activity (excluding DC) comes from the APCD Council, www.apcdcouncil.org/state/map, and input from Anthem, Inc. subject matter experts. The table reflects states that established an APCD and engage in data collection activities. Although Tennessee set up and operated an APCD, as of 2017 the state's APCD is inactive; the rule establishing the APCD was deemed unenforceable. Additionally, three (3) states are in the process of implementing an APCD: Delaware, Hawaii, and West Virginia. Sixteen (16) states have a strong interest in implementing an APCD: Alaska, Arizona, Idaho, Illinois, Iowa, Kentucky, Louisiana, Montana, Nebraska, New Jersey, New Mexico, North Carolina, Ohio, Pennsylvania, Texas, and Wyoming. Eight (8) are not engaged currently in any activities related to APCDs at this time: Alabama, Georgia, Indiana, Mississippi, Missouri, Nevada, North Dakota, and South Dakota.

[†] Indicates states where Anthem currently submits data to the APCD.

ⁱ Categorization of how states are using APCD data is based on information available from the APCD Council, the Anthem Public Policy Institute's review of state APCD websites, and input from Anthem, Inc. subject matter experts.

ⁱⁱ Arkansas is a new APCD market for Anthem. Data submissions began in December 2017.

ⁱⁱⁱ Effective January 2018, Anthem is no longer submitting data to the California Health Performance Information System (CHPI), which is the state's voluntary APCD. However, Anthem continues to submit encounter data for exchange plans to Covered California (mandated as part of participation on the state exchange) and also submits data to Manifest MedEx (formerly Cal Index).

^{iv} Anthem does not make a separate data submission to the state's APCD. Encounter data submissions satisfy the state's APCD reporting requirement.

^v Anthem currently submits Medicaid and Exchange data to the state's database. The submission process for commercial data is in development.

^{vi} Anthem has been granted an exception (waiver) from reporting data to Oregon's APCD through 2018, based on the small number of members covered.

 $^{\rm vii}$ Anthem submitted data to Wisconsin's APCD through December 2017.

Endnotes

- ¹ Information on state APCD activity (excluding DC) comes from: APCD Council. Interactive State Report Map. Retrieved August 30, 2017 from: www.apcdcouncil.org/state/map, as well as input from Anthem, Inc. subject matter experts. The six states with an existing APCD with voluntary data submission include five states that did not mandate an APCD in state statute but where a third-party entity established an APCD in partnership with stakeholders (e.g., providers, payers). The existence of the APCD and submission of data are voluntary. This category also includes a sixth state, Virginia. Although Virginia's APCD was established in statute, the Department of Health partnered with a third party organization, Virginia Health Information (VHI), to operate the APCD. Submission of data to the APCD is voluntary.
- ² APCD Council. (2015, March). All-Payer Claims Database Development Manual: Establishing a Foundation for Health Care Transparency and Informed Decision Making. p. 3. Retrieved August 30, 2017 from: www.apcdcouncil.org/manual.
- ³ APCD Council, p. 15.
- ⁴ Ibid. Per Oregon 442.446, "Healthcare data reporting by health insurers": (1) The Administrator of the Office for Oregon Health Policy and Research shall establish and maintain a program that requires reporting entities to report healthcare data for the following purposes: (a) Determining the maximum capacity and distribution of existing resources allocated to healthcare; (b) Identifying the demands for healthcare; (c) Allowing healthcare policymakers to make informed choices; (d) Evaluating the effectiveness of intervention programs in improving health outcomes; (e) Comparing the costs and effectiveness of various treatment settings and approaches; (f) Providing information to consumers and purchasers of healthcare; (g) Improving the quality and affordability of healthcare and healthcare coverage; (h) Assisting the administrator in furthering the health policies expressed by the Legislative Assembly in ORS 442.025; (i) Evaluating health disparities, including but not limited to disparities related to race and ethnicity.
- ⁵ The 837 form is a submission format that insurers participating on the health insurance exchanges use when sharing data with the Centers for Medicare & Medicaid Services. The X12 form is an electronic data interchange (EDI) format that is used to exchange encounter data between entities. The formats used can vary by state and by specific health insurance program.
- ⁶ Freedman HealthCare, LLC. (n.d.). Releasing APCD Data: How States Balance Privacy and Utility. Retrieved August 30, 2017 from: www.apcdcouncil.org/publication/releasing-apcd-data-how-states-balanceprivacy-and-utility.
- ⁷ Feldman, Joan W., Roberts, William J. (2016, January). APCDs: One Solution to Obtaining Meaningful Performance Data. Retrieved August 30, 2017 from: www.shipmangoodwin.com/apcds-one-solution-to-obtaining-meaningful-performance-data.
- ⁸ Maine Data Health Organization. (2018). CompareMaine. Retrieved December 29, 2017 from: www.comparemaine.org.
- ⁹ See for example: Center for Improving Value in Health Care. (n.d.). Cost of Care. Retrieved December 29, 2017 from: www.civhc.org/get-data/interactive-data/statewide-metrics/cost-of-care. The Colorado APCD site also has interactive reports for service utilization, quality measures, condition prevalence, and price shopping.
- ¹⁰ Cornell Law School, Legal Information Institute. (2017, January 17). 42 CFR Part 2: Confidentiality of Substance Use Disorder Patient Records. Retrieved January 19, 2018 from: www.law.cornell.edu/cfr/text/42/part-2.
- ¹¹ Input from Anthem, Inc. subject matter experts.

¹² Ibid.

- ¹³ Department of Health and Human Services, Substance Abuse and Mental Health Services Administration. (2017, January 18). Confidentiality of Substance Use Disorder Patient Records. 42 CFR Part 2. Federal Register 82, no. 11: 6052-6127. Retrieved December 27, 2017 from: www.federalregister.gov/documents/2017/01/18/2017-00719/ confidentiality-of-substance-use-disorder-patient-records. SAMHSA has since released another final rule, on January 3, 2018, that makes additional changes to 42 CFR Part 2. However, the 2018 final rule has no additional guidance pertaining to APCDs or the APCD operating environment.
- ¹⁴ Supreme Court of the United States. Gobeille, Chair of the Vermont Green Mountain Care Board v. Liberty Mutual Insurance Co. Decided March 1, 2016. Retrieved November 27, 2017 from: www.supremecourt.gov/ opinions/15pdf/14-181_5426.pdf.
- ¹⁵ Federal Trade Commission. (2015, June). FTC Staff Comment Regarding Amendments to the Minnesota Government Data Practices Act Regarding Health Care Contract Data, Which Would Classify Health Plan Provider Contracts As Public Data. Matter Number V150008. Retrieved December 22, 2017 from: www.ftc.gov/ policy/advocacy/advocacy-filings/2015/06/ftc-staff-comment-regarding-amendments-minnesota-government.

¹⁶ Ibid.

- ¹⁷ Koslov, T. and Jex, E. (2015, July). Price Transparency or TMI? Federal Trade Commission, Office of Policy Planning. Retrieved December 22, 2017 from: www.ftc.gov/news-events/blogs/competition-matters/2015/07/ price-transparency-or-tmi.
- ¹⁸ Input from Anthem, Inc. subject matter expert.

¹⁹ Blue Cross Blue Shield Association. (2017, April 13). Letter to the National Committee on Vital and Health Statistics re: All-Payer Claims-based Databases.

²¹ Input from Anthem, Inc. subject matter expert.

²² National Association of Health Data Organizations. (n.d.). Annual Report: Fiscal Year 2017. Retrieved January 2, 2018 from: www.nahdo.org/sites/nahdo.org/files/Annual_Report/2017%20annual%20report.pdf.

 $^{\rm 23}$ Input from Anthem, Inc. subject matter expert.

24 Ibid.

- ²⁵ Turney, S. (2016, June 17). Anthem, Inc. Testimony before the National Committee on Vital Statistics on Claims-based Databases for Policy Development and Evaluation. Retrieved January 18, 2018 from: www.ncvhs.hhs.gov/wp-content/uploads/2016/05/Panel-3-Sheryl-Turney-Anthem-2016June17.pdf.
- ²⁶ Blue Cross Blue Shield Association.

²⁰ Ibid.

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Anthem's Public Policy Institute was established to share data and insights to inform public policy and shape the healthcare programs of the future. The Public Policy Institute strives to be an objective and credible contributor to healthcare innovation and transformation through publication of policy-relevant data analysis, timely research, and insights from Anthem's innovative programs.

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