



NEW YORK'S ALL-PAYER DATABASE:
**A New Lens for
Consumer Transparency**

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About the New York State Health Foundation

The New York State Health Foundation (NYSHealth) is a private, statewide foundation dedicated to improving the health of all New Yorkers, especially the most vulnerable. Today, NYSHealth concentrates its work in three strategic priority areas: expanding health care coverage, building healthy communities, and advancing primary care. The Foundation is committed to making grants, informing health care policy and practice, spreading effective programs to improve the health system, serving as a neutral convener of health leaders across the State, and providing technical assistance to its grantees and partners.

About the APCD Council

The APCD Council is a learning collaborative of government, private, non-profit, and academic organizations focused on improving the development and deployment of state-based all payer claims databases (APCDs). The APCD Council is convened and coordinated by the Institute for Health Policy and Practice (IHPP) at the University of New Hampshire (UNH) and the National Association of Health Data Organizations (NAHDO). The Council's work focuses on shared learning amongst APCD stakeholders, early stage technical assistance to states, and catalyzing states to achieve mutual goals.

Executive Summary

BACKGROUND AND PURPOSE

More than four years ago, in 2011, New York State passed legislation enabling the creation of an all-payer database (APD).¹ An all-payer claims database (APCD) is a database, often created by state mandate, that consolidates encounter and payment data (medical claims) across all payers—Medicare, Medicaid, and commercial insurers—and houses valuable information on health care costs and prices; services and encounters; payer comparisons; and quality indicators. In New York State’s vision, the claims data will be integrated with clinical and quality data and public health repositories to create a more robust resource—the APD.

Without an APD in New York State, knowledge about health care costs and utilization remains limited because of the lack of data regarding health care spending, limited State resources to collect data, and limited reporting requirements to generate information that has actual bearing on prices and costs. Likewise, without an APD, limited resources exist to help policymakers examine population health trends at the local, regional, and State levels; enable researchers to examine variation in health care access, utilization, and outcomes among patients; and spur providers to improve quality through performance benchmarking.

The State has championed the APD’s creation, allocated funding for it through the State budget and federal grants, and considers it a future resource for quality oversight, health services research, price transparency, and health care transformation. The development of an APD is seen by many as critical to support consumer engagement, price transparency, payment and delivery system reforms, and goal setting for improved outcomes.

A number of developments in New York are driving interest in the APD’s implementation among stakeholders (e.g., consumers, payers, providers, researchers, employers, and government policymakers). For example, news reports increasingly highlight the need for consumers to have more transparency of provider networks, provider quality, premium pricing, and provider pricing. In addition, the Affordable Care Act (ACA) ushered in a new era of consumers independently buying insurance products online through health benefit exchanges, an influx of narrow network products in the insurance market, and a greater need for health system and health insurance literacy among consumers. The growth in high-deductible plans is resulting in consumers more aware—and in need—of price and quality information. A wave of consumer-facing technology applications in the health care sector has raised consumers’ expectations

¹ This report uses the acronyms APD and APCD. Whereas, nationally, most states use the term APCD to describe their claims-based analytic platforms, New York calls its system an APD. The New York definition extends beyond claims also to include clinical and population health data. This report uses the term APD when referring to New York’s solution and APCD when referring to those in other states.

Executive Summary *(continued)*

regarding what information should be readily available. Significant State investments are being made to transform health care payment, delivery, and outcomes (e.g., Delivery System Reform Incentive Payment program, or DSRIP; State Health Innovation Plan, or SHIP; Population Health Improvement Program, or PHIP).

At this timely moment, before the APD's regulations and policies have been fully formed, an independent, external analysis may provide the context needed for State policymakers to make the decisions that will most benefit New Yorkers.

This report was commissioned by NYSHHealth to help preserve an expansive vision for the APD and elevate the public's interest in determining the extent of its powers. It aims to address the key issues that confront New York State policymakers and make recommendations on the choices before them. This report captures lessons from other states that have either developed, or are developing, similar systems and highlights the perspectives of key stakeholders in New York.

THE NEW YORK OPPORTUNITY

Since 1979, New York's Statewide Planning and Research Cooperative System (SPARCS)² has been successfully collecting hospital-related discharge data and re-releasing that information publicly to research institutions, providers, and other data requestors. Although SPARCS data hold a comprehensive picture of hospital inpatient and outpatient (ambulatory services, emergency department, and outpatient services) visits, they do not contain financial information beyond charges. Because SPARCS is focused on hospital care, services, such as nonhospital primary care visits, specialty care visits, and pharmacy data, are not included.

Legislative Models for New York

Catalyst for Payment Reform and Health Care Incentives Improvement Institute released their annual report card on state price transparency in July 2015. Entitled "Report Card on State Price Transparency Laws," it awards only five states in the country a grade of C or better. Vermont and Virginia each received C grades; Maine and Colorado each received B grades; and New Hampshire was the only state to receive an A. Massachusetts' ranking dropped from an A to an F after the state ended its publicly accessible website for consumers to look up price and quality information, drawn from the state's APCD. New York is cited in the report as "still assembling their all-payer claims database." The authors of the report state that "the most promising price transparency legislation requires that health care providers and insurance plans provide patients with:

- A good-faith estimate of the patient's out-of-pocket expenses that are specific to the patient's insurance plan, health care needs, and health care provider;
- Quality information on individual physicians and providers; and
- Access to this information in real time via a website, personal electronic device, or Electronic Medical Record (EMR) system."

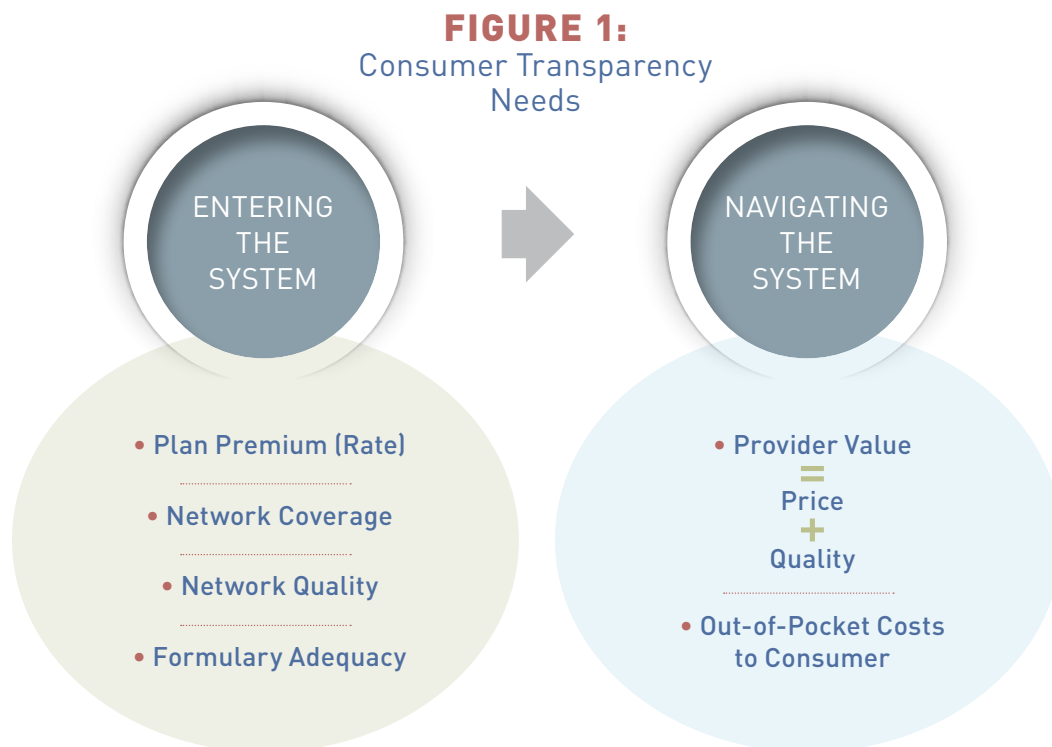
These three goals for state transparency legislation are all feasible in New York's current APD effort.

² Learn more at: <https://www.health.ny.gov/statistics/sparcs/>.

Executive Summary (continued)

When New York updated the legislation governing SPARCS to include the collection of data from all payers for all services, the enabling mechanism for the New York APD was created. The intent of this database is to collect claims data from all commercial and public payers (Medicare and Medicaid) in New York to “provide a more complete and accurate picture of the health care delivery system.”³ Broadly, the APD project is working to integrate claims data, hospital discharge data (SPARCS), and clinical data (regional health information organizations, or RHIOs) across payers to create a unique data set for New York to support policy development, research, and, perhaps in the future, operational needs at the provider level.

Though this vision for an integrated data platform is bold, there is not yet a unified stakeholder vision in New York as to how consumer transparency efforts supported by the APD should be defined, financed, or implemented. As shown in **Figure 1**, there are many needs related to transparency. It is clear from the interviews conducted for this report that New York’s APD can play a major role in improving transparency: there is almost near-consensus that consumers currently have poor transparency into the health care system, both when purchasing insurance products and when using them, as described further in the Key Findings chapter of this report.



³ Learn more at: https://www.health.ny.gov/technology/all_payer_database/.

Executive Summary *(continued)*

Consumer transparency efforts exist in different forms, whether it be a consumer portal for price and quality data or research to drive policy decisions that maximize the public interest. Existing consumer tools and information are limited and fragmented. To date, the true price of services has been masked. Similarly, data about quality of care are inconsistently measured and not reported in a way that is easy for provider value to be determined. Commercial insurance products are becoming more fragmented with limited (narrow) provider network products that add additional layers of confusion.

To counter and address some of these issues, New York State is developing the APD with the goal of providing administrative and clinical information in a single utility to be used for transparency, policy, and other purposes. The research community is especially interested in obtaining access to these data for econometric, quality, and policy research. Consumer advocacy organizations have expectations of price and quality data being developed to assist consumers in navigating the health care system. Employers see opportunities to support payment reform efforts alongside employee engagement strategies. With the development of the New York APD, providers, payers, researchers, policymakers, and others focused on payment reform would have access to a data set for setting payment targets, evaluating reform efforts, and developing new policies. In short, the intent is for the State to develop the APD as an analytic tool that provides something for everyone.

SUMMARY OF NEW YORK'S APD PROGRESS AND FUTURE PLANS

In the spring 2011, New York State enacted legislation authorizing the creation of an APD to develop transparency tools and provide the information systems required to help support health reform efforts. In the four years since, progress has been made, resulting in the development of a data intake solution, an interim APD hosting solution, and a request for proposals for a data analytics vendor solution. This work has taken place alongside other major State initiatives, including the development of New York's health information exchange (Statewide Health Information Network for New York, or SHIN-NY) and health benefit exchange (NY State of Health Marketplace).

Full implementation of the New York APD is anticipated in 2016. In advance of this milestone, the final regulations and supporting policies are being drafted to ensure that the resulting system meets the needs of all stakeholders, including policymakers, consumers, employers, researchers, providers, and payers. New York's challenge is to define a system that will meet a variety of needs, including using these data to guide policy, resource allocation, and health system reform efforts as they grow in scope and usefulness.

The New York APD currently is managed by the New York State Department of Health (NYSDOH), but also is designed to serve the needs of the New York State Department of Financial Services (NYDFS). NYDFS manages the regulation of commercial health insurance plans and plans to use the APD to support rate review and other policy analysis.

Executive Summary *(continued)*

As implementation of the APD draws closer, individuals in support of, and in opposition to, new levels of data transparency have voiced concerns. To best inform both the regulations and the implementation of the APD, New York State would benefit from lessons from other states and entities with experience in this area. In other states, payers typically have expressed concern over the development of APCDs for two reasons: **(1)** they view the requirement to deliver data to the state as an unfunded mandate and **(2)** they believe provider payment information should not be disclosed through consumer transparency efforts. The latter issue typically is expressed as an issue of anti-trust; however, states have reviewed this issue and believe the concern is manageable. As an example, in Colorado, the APCD managing entity, Center for Improving Value in Health Care (CIVHC), has published guidance that it uses to address the concerns.

To date, the consumer-use cases for New York—primarily access to cost and quality information—have not been fully defined. Other states have developed consumer pricing and quality tools using their APCDs, and these are models for New York to consider. To fully realize these models, however, there must be supporting regulations for collection and release of the data. Therefore, there is an opportunity in New York for consumer voices to be heard as the regulations are being finalized.

Similar to other states with APCDs, New York's successful implementation of the APD is critical to the long-term success of numerous health reform initiatives, including the State Innovation Model testing grant and DSRIP. Guidance, input, and lessons learned from stakeholders and other states will inform New York policy with respect to implementing the APD and ensuring a high-performing initiative that supports, informs, and promotes high-quality and high-value care for all New Yorkers.

KEY FINDINGS AND RECOMMENDATIONS SUMMARY

The following seven findings and five recommendations are discussed in detail in later chapters of this report.

Key Findings:

Reliable and trusted price and quality data for consumers are scarce. Similar to other states, New York consumers have few data sources available to them to help navigate the purchase of health insurance, and then navigate the health care system once they have obtained coverage. The stakeholders interviewed for this report could not cite any single source of reliable and trusted pricing and quality data for consumer consumption. Consumers are looking for information regarding provider networks, formularies, insurance product value, provider procedure price, provider quality, and provider value. To adequately create a complete picture of quality, price, and value, the New York APD will be the primary data source that contains comprehensive information across payers and geographies.

Executive Summary *(continued)*

2 Pricing data versus charge data are required for true transparency. Procedure charge information is considered the list price for a procedure and is limited in its usefulness for price transparency, given that payer-provider contracts do not historically reimburse providers for charges. Individual payers typically negotiate rates based on per diem amounts, discounts off of charges, or fee schedules that are often indexed to Medicare diagnosis-related group (DRG) payments. Interviewed stakeholders representing consumer interests (e.g., consumer organizations, employers, researchers) have stated that the paid amount is most relevant and is required for true system transparency. As one provider interviewed for this report aptly stated, “Charge information is yesterday’s news.” It is recommended that the New York APD not only collect pricing data, but also release it via consumer portals, to researchers and through other data release policies.

3 Transparency is more complex than price shopping. The stakeholders interviewed for this report stated that to meet New York’s transparency needs, any systems or information created for consumers would need to be factual, credible, timely, integrated across payers and provider networks, objective, and clear. Consumers need information both at the point of purchasing an insurance product and when they are accessing benefits and provider services. It is recommended that the New York APD recognize and address the fact that consumers need to understand value in two fundamental ways: **(1)** the value of the benefit packages offered between carriers, or which plan benefits ensure access to high-quality, high-value care and **(2)** provider value, or which providers that patients wish to access have the best outcomes at the lowest price.

4 The State’s vision, goals, and timeline for the APD are unclear to stakeholders. During the stakeholder interviews, there was an almost universal lack of clarity of the vision, goals, and timeline for the APD. Most stakeholders understood that claims data would be collected—and the majority expected information for consumers and researchers to be provided—but nearly all cited a lack of basic understanding of the APD mission. Without solid stakeholder knowledge and support, the ability to develop an APD system and program is hampered. At the most basic level, the feelings of disconnectedness and uncertainty in the stakeholder community can be politically destructive and self-undermining to the work that the State is trying to accomplish. This lack of clarity by the stakeholders is an opportunity for the State to seize—engaging stakeholders in the plans for the APD can re-energize them to the APD development process.

5 The New York APD is viewed as a public utility with unclear governance. According to the majority of New York’s APD stakeholders interviewed, the APD is seen as a public utility model designed to fulfill a social contract between the State and its citizens, whose data reside in the APD. This social contract begins with the fact that

Executive Summary *(continued)*

the APD is funded with public tax dollars, both State and federal; therefore, the stakeholders believe the data should be used to benefit the public. Additionally, the stakeholders believe that the State has a responsibility to be the one to guarantee the privacy of individuals' data held within the system—with privilege comes responsibility. The New York stakeholder interviews also revealed a lack of understanding of the APD program's governance structure. Most believed it to be housed by the NYSDOH, whereas others were also aware that NYSDFS has APD interests as well, such as rate review audits. About half were aware of the State's Health Information Technology (HIT) workgroup,⁴ but most that were aware did not know if the HIT workgroup had any management or authority functions for the APD. The other component of governance discussed was data release management, and there was no clear understanding of how the APD data release process will be managed.

6 A broad consumer strategy across State agencies will require concerted effort and coordination. The majority of the stakeholders, as well as the other APCD states interviewed, identified the need for the development of a broad consumer strategy across State agencies—health (NYSDOH), insurance (NYSDFS), employees (New York State Department of Civil Service, or NYSDCS), Medicaid, and the Marketplace (NY State of Health). Each of these agencies impacts consumers in various ways, including population health improvement efforts, health reform, insurance coverage, and quality of care. Each of these agencies desires access to the APD to support research, State policy initiatives, consumer transparency tools, system performance, rate review, clinical operations, the Triple Aim,⁵ and other efforts. To support these various internal State needs, a broad consumer strategy needs to be developed to coordinate APD resources and uses across State agencies.

7 Fiscal and programmatic sustainability likely will be an ongoing challenge. Though the development of an APD has many clear benefits to public policy, research, employers, and consumers, benefits to providers and payers have sometimes been less clear for states with APCDs. This lack of clarity of value from providers and payers has led to sustainability challenges in some other states. Some of these challenges have been programmatic, whereas others have been fiscal. To better build broad support and reduce challenges to either programmatic or fiscal sustainability, New York will need to clearly define to stakeholders, legislators, and the Governor's office the use cases that the APD will support. Additionally, the ongoing programmatic investment will need to be defined along with a sustainability strategy. One researcher aptly stated that the "State needs political resolve to see this through."

⁴ Learn more at https://www.health.ny.gov/technology/innovation_plan_initiative/workgroups.htm.

⁵ Learn more at: <http://www.ihl.org/Engage/Initiatives/TripleAim/Pages/default.aspx>.

Executive Summary (continued)

Recommendations:

1 Develop a phased approach to APD data release based upon use cases. This approach will help define the program, as well as manage stakeholder expectations. During the stakeholder interview process, five categories of use cases were identified: research, support for State policy initiatives, transparency tools, system performance, and clinical operations. Each of the above categories is further described in the Recommendations chapter of this report.

2 Develop price transparency tools. The majority of the stakeholders interviewed believe that the State has a responsibility to develop price transparency tools for the New York consumer marketplace. Information about health plans, provider networks, procedure pricing, utilization, and charge-to-price ratios should be included. The authors of this report acknowledge that a price transparency site developed by New York may not be able to provide consumers with the precise out-of-pocket costs that reflect deductibles and other consumer liabilities, as this information is most accurately accessed from the consumer's health plan. However, multiple states the authors spoke with in the development of this report responded that states have a responsibility to deliver this information, if only to help keep pressure on the industry regarding price and quality transparency.

3 Include self-funded data sources in the APD. In most states, New York included, between 30-50% of the commercially insured population falls under self-funded, Employee Retirement Income Security Act of 1974 (ERISA) benefit plan arrangements. These plans typically are administered by health plans or third-party administrators. For the New York APD to truly be an all-payer database, inclusion of these self-funded data sources in the data collection is imperative. Given the historical collection of other states, the need to include self-funded data to create an APD, and the support of New York's Attorney General to collect such data, the authors of this report recommend that the State move ahead with its proposal to include data from self-funded plans in the New York APD data collection regulations when they are released.

4 Develop a stakeholder engagement and communications process regarding the APD startup functions. To develop stronger stakeholder understanding, engagement, and support, it is recommended that New York develop an engagement and communications process regarding the APD startup functions currently under development. Stakeholders need to understand the programmatic and policy governance structures to bring a more unified, supportive group of stakeholders to the table. The previously developed APD steering committee should be restructured to create a mechanism for stakeholder input and support. As it moves forward, New York, at a minimum, should address the following two areas: **(1)** the finalization and articulation of the APD governance structure, both programmatic and policywise and **(2)** a formalized stakeholder communications strategy.

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5 Formalize an APD data quality program. Universally among those interviewed for this report, data quality was considered to be of paramount importance to New York's APD program development for both trust in and usefulness of the APD. Building on the State's existing data quality procedures, an additional process for achieving continuous feedback from data users would result in more accurate information over the long term. It is recommended that New York, at a minimum, develops a process to include input and review of data by submitters (payers) and those being reported on (providers). Other states have indicated that review of reports by payers and providers has been key to data quality. It is recommended that the State develop and formalize such a program as part of its startup operations. Another way to increase data quality would be to include researchers very early on in the data release and data quality process. Researchers who have worked previously with claims data sets will possess the skills required to assist the State's APD team in carrying out the data quality plan. Several researchers interviewed for this report cited a desire for tighter integration with the State's APD program, and having researchers involved in data quality work is one possible way to accomplish this.

Methodology

NYSHealth retained the [APCD Council](#) in March 2015 to conduct research that would help guide New York State’s APD efforts, specifically around the issue of consumer transparency. The research (background review and interviews) was conducted between April and June 2015, resulting in a synthesis of findings of two major groups: New York stakeholders and states with APCDs.

The New York stakeholder research consisted of a total of 55 interviews with individuals representing consumer organizations, researchers, employers, payers, providers, and RHIOs. More than a dozen individuals interviewed currently serve or previously served on State project committees, including the HIT workgroup.

All New York stakeholder interviews were conducted confidentially and were structured using an interview guide co-developed by NYSHealth and the APCD Council. Questions developed for the interview guide were based on the following topics:

- Understanding of the New York APD
- What Is Transparency?
- Use Cases for the New York APD
- Data Collection
- Data Linkage and Release
- Policy
- Stakeholder Roles
- State Perspectives/Lessons Learned

A second set of interviews included 17 states that were in various stages of implementation of their APCDs. The state interviews were less formal and were conducted by the APCD Council staff in May and June 2015. These states were contacted to understand their consumer strategies, progress to date, challenges, and lessons learned.

Methodology (continued)

The interviews with New York stakeholders and states with APCDs conducted for this report were far-reaching in terms of the conversation topics. The findings and conclusions of this report were drawn from and covered the following 12 discussion domains:

• Use Cases and Stakeholders
• Research Needs
• Consumer Transparency Continuum
• Charges, Cost, and Price
• Provider Value Equation
• Consumer Transparency Websites
• Governance
• Privacy
• Data Collection
• Data Quality
• Data Release and Fees
• State Lessons Learned

In most cases, depending on the stakeholder group or individual interviewed, there was a deeper dive in a specific topic area during the interview. For example, a researcher might have discussed his/her specific research needs, as well as data release and data quality, whereas a consumer representative more likely would be focused on transparency website development and how to maintain patient privacy.

Finally, interviews with the NYSDOH and NYSDFS were held in March 2015 to understand the APD's history, current status, and future plans. Other relevant materials from other states and New York (e.g., regulations, websites) were also reviewed. Together with the two sets of interviews, the findings and recommendations included in this report were developed.

National Transparency Climate

EVOLUTION OF STATES

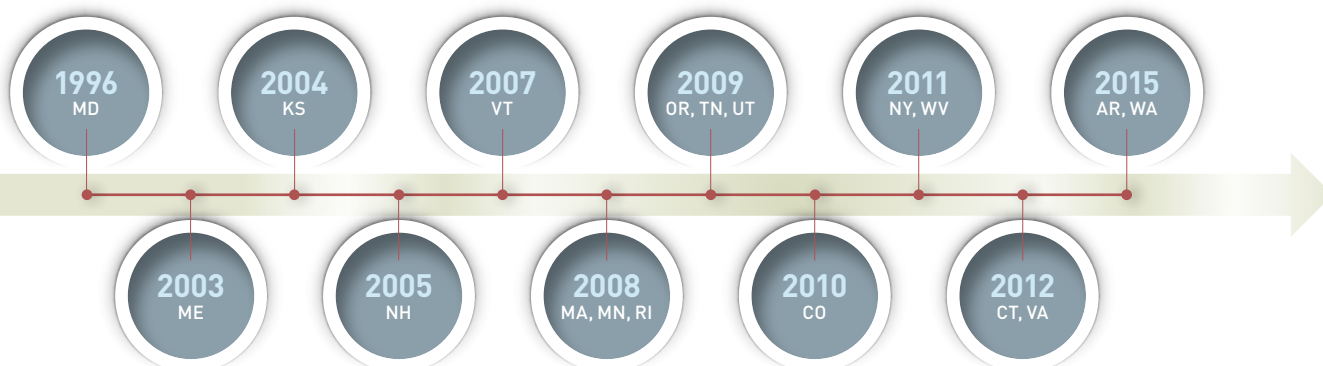
The passage of the Health Information Technology for Economic and Clinical Health Act and the ACA provided states with more resources to be able to focus efforts on health care transparency. With these new resources, states developed or invested in a plethora of efforts focused on supporting health care reform, including electronic health records, health information exchanges, health benefit exchanges, patient-centered medical homes, accountable care organizations, and APCDs.

States had historically developed APCDs to support or understand a variety of health and health care topics, including:

<ul style="list-style-type: none"> Population health measurement (e.g., disease condition, geography, payer) 	<ul style="list-style-type: none"> Utilization (e.g., total, type of service, procedure, provider, payer) 	<ul style="list-style-type: none"> Expenditures (e.g., total, type of service, procedure, provider, payer) 	<ul style="list-style-type: none"> Health care transparency (e.g., procedure, episode, provider, payer) 	<ul style="list-style-type: none"> Health reform (e.g., Triple Aim, provider benchmarking, payment reform)
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Twelve states have passed APCD legislation and have fully implemented their APCDs (Colorado, Kansas, Maine, Maryland, Massachusetts, Minnesota, New Hampshire, Oregon, Rhode Island, Tennessee, Utah, Vermont); six states, including New York, have passed legislation and are in various stages of implementation of their APCDs (Arkansas, Connecticut, Nebraska, New York, Washington, West Virginia); and three states have established voluntary claims databases⁶ (California, Wisconsin, Virginia⁷).⁸ A timeline of APCD development is detailed in **Figure 2**.

FIGURE 2: APCD Legislation Timeline



⁶ Other voluntary efforts exist, but many are not statewide and are not included here.

⁷ Virginia receives voluntary payer submissions, but the APCD is created legislatively. Both California (<http://www.chpis.org/>) and Wisconsin (<http://www.wisconsinhealthinfo.org>) have voluntary, nonlegislatively created databases.

⁸ Learn more at: www.apcdouncil.org.

National Transparency Climate *(continued)*

The majority of the state databases contain data from all payers: fully insured commercial, self-funded commercial, Medicaid, and Medicare. Claims typically are supplied for medical, pharmacy, and oral health services to create a longitudinal record.

Almost all states have governance models that are based within state agencies, such as health or insurance departments; however, three states (Colorado, Connecticut, and Virginia) legislatively authorize nonprofit entities to create and manage their APCDs. This is a relatively recent development by states and appears to provide flexibility, additional levels of accountability, and connectivity with other state reform efforts, including health benefit exchanges. Whereas some states early on created their APCD systems to stand alone, with the potential of future linkage to other systems (e.g., registries and clinical data sets), other states, such as New York and Connecticut, are planning to implement systems that integrate administrative claims and clinical data from the start. This course of action reflects lessons learned from existing APCDs' inability to easily link to other systems (because of standardization issues, lack of master patient index, and other issues). It is becoming clear that health reform efforts, particularly payment reform, would benefit greatly from integrated data sets.


It also is becoming clear to the APCD Council that development of a consistent state transparency strategy to include activities that most states are performing independently (e.g., building consumer transparency websites, convening transparency or consumer advisory groups and boards, passing legislation focused on transparency, and linking health care data sets) could help states streamline health reform efforts. Based on state interviews conducted for this report, many are currently discussing a formal transparency strategy for sharing information with various constituencies (e.g., consumer, provider, payer) and coordinating efforts across state agencies. In the minority, Connecticut, Utah, and Vermont all have stated that they have developed formal transparency strategies.

Although many states have been working with their APCD systems for years, many are refocusing efforts on transparency. Descriptions of a sample of states' experiences, lessons learned, and insights regarding transparency are detailed below.


COLORADO: Although a comprehensive transparency strategy does not exist in Colorado, the state does have a broad HIT strategy, which guided the legislation to develop the APCD; established the convening organization, CIVHC; created an APCD advisory committee and a data and transparency committee (both of which have consumer representation that drives APCD reporting and research); and created a consumer transparency website, CO Medical Price Compare (www.comedprice.org). The CO Medical Price Compare website shows utilization rates and median amounts paid for select medical services, by facility. The reflected median is based on a combination of payer payments (commercial, Medicaid, or uninsured estimates if no insurance coverage) and patient paid amounts.

National Transparency Climate *(continued)*

The language in Colorado's legislation ensures that the administrator of the APCD will provide timely, complete, and publicly available cost and utilization data to consumers (and other stakeholders):

 **...Section 5 (d)** Determining the measures necessary to implement the reporting requirements in a manner that is cost effective and reasonable for data sources and timely, relevant, and reliable for consumers...;**(f)** collect, aggregate, distribute and publicly report performance data on quality, health outcomes, health disparities, cost, utilization and pricing in a manner accessible for consumers...”⁹

Although Colorado's initial legislation provided language ensuring that the system would serve public interests, it did not address the collection of self-funded claims, despite that approximately 30% of those insured in the state are covered under self-insured employer claims. To address this gap, a rule change was required to amend the definition of a private health care payer to include self-insured employer-sponsored health plans. The following language was added to address the gap:

 **...** For the purposes of this regulation, a “private health care payer” also means a self-insured employer-sponsored health plan covering an aggregate of 100 or more enrolled lives in Colorado. It does not include a self-insured employer-sponsored health plan, if such health plan is administered by a third-party administrator or administrative services only organization that services less than an aggregate of 1,000 enrolled lives in Colorado.”


The rule change was promulgated on June 29, 2015, and the new rule went into effect August 30, 2015. The addition of these claims will provide greater reporting breadth and accuracy.

CONNECTICUT: Access Health CT (AHCT), the convener of Connecticut's APCD and health benefit exchange, has a governance model described as a business sustainable model, as it does not reside within state government but rather as a quasi-public agency, similar to Colorado and Virginia. The focus of AHCT's transparency strategy centers on the development of consumer transparency reporting. AHCT employs an advisory group and board of directors, which include consumer representation.

⁹ Learn more at:
http://www.leg.state.co.us/clics/clics2010a/csl.nsf/fsbillcont/7772EFE1E998E627872576B700617FA4?Open&file=1330_enr.pdf.

National Transparency Climate *(continued)*

Connecticut's APCD legislative language is very specific to ensuring that the data are used in a way that supports consumers:

 **...Sec. 1(e)** Utilize data in the all-payer claims database to provide health care consumers in the state with information concerning the cost and quality of health care services that allows such consumers to make economically sound and medically appropriate health care decisions ...”¹⁰

Currently, AHCT is developing a consumer decision support tool to assist consumers in Connecticut in choosing the right health plan from the health benefit exchange based on information regarding an individual's premium, advanced premium tax credit, cost share reductions, and expected out-of-pocket costs for medical and/or pharmacy utilization based on past or projected illness burden of the family.

In regards to linking claims data to other data sets, the legislative language does not specifically prohibit linking; however, no current rules or policies are in place for how linking can occur. If the state wanted to link to clinical or other data, as is desired in New York, a policy and potentially a new administrative rule would need to be put in place.

MAINE: The Maine Health Data Organization (MHDO), which is the manager of the state's APCD, was established by the Maine Legislature in 1996 as an independent executive agency to collect clinical and financial health care information and make this information accessible to the public. MHDO policy is established by a board that represents health care providers, payers, and consumers. This board has been thinking about a comprehensive transparency strategy for years, although one has not been formalized. MHDO also operates the Maine HealthCost consumer transparency website (<https://mhdo.maine.gov/healthcost2014/>), which presents the average payment amount of medical procedures by facilities, using Maine APCD data. Based on feedback by the state's consumer advisory committee, the website soon will add quality measures and increase the number of procedures available.


Recently, the MHDO board created a subcommittee to discuss whether and how the state should link clinical data to claims—a recommendation to the full MHDO board is expected in September 2015. This recommendation will determine whether MDHO will move forward with changing data collection rules to support integration, something that does not exist in the rules at this time.

¹⁰ Learn more at: <https://www.cga.ct.gov/2012/ACT/Pa/pdf/2012PA-00166-R00HB-05038-PA.pdf>.

National Transparency Climate *(continued)*

MARYLAND: The Maryland Health Care Commission manages the state's APCD, primary care medical home program, and quality reporting on behalf of the state. The state is developing multiple consumer websites to support consumer transparency, including a price transparency portal with paid amount information and a cost-and-utilization tool with portals for consumers and providers.

MASSACHUSETTS: The Center for Health Information and Analysis (CHIA) is an independent state agency that serves as the state's health care data center. CHIA was created through legislation that was enacted to "improve health care quality and contain health care costs through transparency, efficiency and innovation."¹¹ CHIA provides health care data (including APCD data sets) and analysis to inform policy decisions in Massachusetts. Recent analysis includes a total health care expenditures report,¹² which details per capita spending for health care in Massachusetts. Of note, Massachusetts previously had an active consumer website (My Health Care Options), which provided service-level cost and quality data to consumers by procedure. However, in 2012, because of funding cuts, as well as the reorganization of the state agency infrastructure and priorities, the website was discontinued. The following language, within the legislation that created CHIA, demonstrates the state's commitment to the establishment and maintenance of a consumer website for cost and quality information.

 **Section 20. (a)** The center, in consultation with commission, the executive office of health and human services, the department of public health and such other agencies or authorities as it deems appropriate, shall maintain a consumer health information website. The website shall contain information comparing the quality, price and cost of health care services. The website shall also provide information about provider and payer achievement of cost benchmarks and growth goals. The website may also contain general health care information as the center considers appropriate. The website shall be designed to assist consumers in making informed decisions regarding their medical care and informed choices among health care providers. Information shall be presented in a format that is understandable to the average consumer. The center shall publicize the availability of its website.

¹¹ Learn more at: <https://malegislature.gov/Laws/GeneralLaws/PartI/TitleII/Chapter12C>.

¹² Learn more at: <http://www.chiamass.gov/total-health-care-expenditures>.

National Transparency Climate *(continued)*

(b) The website shall provide updated information on a regular basis, at least annually, and additional comparative quality, price and cost information shall be published as determined by the center. To the extent possible, the website shall include: (1) comparative price and cost information for the most common referral or prescribed services, as determined by the center, categorized by payer and listed by facility, provider, and provider organization or other groupings, as determined by the center...

(c) The center shall develop and adopt, on an annual basis, a reporting plan specifying the quality and cost measures to be included on the consumer health information website and the security measures used to maintain confidentiality and preserve the integrity of the data. In developing the reporting plan, the center, to the extent possible, shall collaborate with other organizations or state or federal agencies that develop, collect and publicly report health care quality and cost measures and the center shall give priority to those measures that are already available in the public domain. As part of the reporting plan, the center shall determine for each service the comparative information to be included on the consumer health information website.

(d) In designing and maintaining the website, the center may conduct research regarding ease of use of the website by health care consumers, consult with organizations that represent health care consumers, and conduct focus groups that represent a cross section of health care consumers in the commonwealth, including low income consumers and consumers with limited literacy. The website shall comply with the Americans with Disabilities Act.”¹³

MINNESOTA: In 2008, Minnesota passed health reform legislation, which among other initiatives created the Minnesota APCD. Guided by Minnesota’s strict privacy laws, use of the Minnesota APCD was restricted to the transparency initiative for which it was created; the 2008 legislation did not envision use of data for broader purposes or by users other than the state’s health department. The 2014 Legislature reprioritized the use of the Minnesota APCD by suspending the transparency initiative in favor of analyses on cost, quality, access, and disease burden, in addition to certain evaluation studies. The legislation also directed


¹³ Learn more at: <https://malegislature.gov/Laws/GeneralLaws/PartI/TitleII/Chapter12C/Section20>.

National Transparency Climate *(continued)*

the state's health department to convene a stakeholder discussion about broader use of the data. The stakeholders proposed an iterative approach to broader data use that resulted in the passage of legislation directing the state's health department to create public use files.¹⁴

NEW HAMPSHIRE: The state's consumer transparency website, NH HealthCost (<http://nhhealthcost.nh.gov/>), was developed in 2006 by the New Hampshire Insurance Department, using the state's all-payer claims data, to improve the price transparency of health care services in New Hampshire. The website provides cost estimates—specifically, median rates for out-of-pocket patient payments and payer payments to the provider—for specific medical procedures by provider groups. The site also provides estimates for individuals who are uninsured. The NH HealthCost site is currently undergoing development to add additional procedures for bundled services,¹⁵ unbundled services, dental claims, and pharmacy claims. The redesign project was developed partially in response to a 2014 grade of F for New Hampshire in the Catalyst for Payment Reform's annual report card on state price transparency laws. This year, however, New Hampshire was the only state in the country to earn a grade of A for access to health care prices.¹⁶

OREGON: The Oregon Health Authority (OHA), which runs Oregon's All Payer All Claims (APAC) database, is working on a strategic transparency plan with its APAC public use advisory group to advise the state on the creation and publication of public use data sets related to the APAC database. The advisory group will address issues relating to the types of public use data sets that would best serve the public interest. In addition, Oregon's APAC legislation included references to making the data available to Oregon programs for the purpose of leveraging ongoing community efforts aimed at improving quality in health care:

 **...(5)** The Administrator of the Office for Oregon Health Policy and Research shall use data collected under this section to provide information to consumers of health care to empower the consumers to make economically sound and medically appropriate decisions. The information must include, but not be limited to, the prices and quality of health care services...¹⁷

Further, prior to building a transparency website or defining other uses of the data, OHA is seeking to understand what consumers want to see (e.g., website, mobile app) and how to aid deficits in consumers' health care literacy, so that the information relayed is used effectively.

¹⁴ Learn more at: <https://www.revisor.mn.gov/laws/?id=178&doctype=Chapter&year=2014&type=0>.

¹⁵ For a given procedure, all other procedures, services, and supplies billed on the same day for the same person are summed together and included in the total cost to create a bundle. Bundles may include procedures performed by multiple providers.

¹⁶ Learn more at: http://www.catalyzepaymentreform.org/images/documents/2015_Report_PriceTransLaws_06.pdf.

¹⁷ Learn more at: <http://www.oregon.gov/oha/ohpr/Pages/Statutes-Health%20Care%20Data%20Reporting.aspx>.

National Transparency Climate *(continued)*

At this time, OHA is considering how to collect this information (e.g., focus groups, survey) and hopes to have a plan of action by the end of 2015.

Most recently, Oregon's Governor signed S.B. 900¹⁸ (effective August 12, 2015) that will allow the state to collect patient identifiers to enable linkage of its existing claims data to clinical data sets and the health benefit exchange.

RHODE ISLAND: Legislation establishing an APCD was passed in 2008; however, the legislation did not provide funding for the state's Department of Health to develop and operate an APCD. The lack of funding caused delays in mobilizing APCD development efforts, demonstrating the importance of addressing funding as part of the APCD planning activities. Since then, the Department of Health has obtained a series of federal grants to support startup operations and data collection. This funding also has allowed the state to begin developing guidelines for data release and custom reporting. The state also is working on static reports highlighting total-cost-of-care measures, health care utilization, and population health; these reports will be posted publicly upon completion.

TENNESSEE: Although Tennessee passed APCD legislation in 2009, the state still considers itself new to the APCD scene. This is as a result of, in large part, a major reorganization of the APCD's managing department coupled with a concurrent change in its data collection vendor in late 2011; until a new data collection vendor was in place in late 2013, Tennessee experienced a hiatus in claims data collection.¹⁹ Currently, the state is focusing its efforts on the operational pieces of its APCD and has, as part of state statute, reconvened the Tennessee Health Information Committee to oversee data management activities of the APCD.

Although there was early interest in linking its claims data to other data sets, there is a bill in the current Legislature that will restrict personal identifiers at collection, potentially making data linkage impossible.

UTAH: The Utah Health Department, which manages Utah's APCD, is supporting a pilot project that would link Utah claims data to its vital records database. To support this work, Utah is developing a master person linkage system that would allow the ability to identify a person across data sets for the purpose of linkage. This model could potentially help inform linkage efforts in New York between claims and clinical data sets.

VERMONT: The Green Mountain Care Board, which manages the state's APCD (among other activities), was established via legislative mandate to advise on transparency efforts on behalf of the state. Vermont conducted focus groups to find out what Vermonters want in developing its consumer-based transparency strategy; results of this focus group are pending.

¹⁸ Learn more at: <https://olis.leg.state.or.us/liz/2015R1/Downloads/MeasureDocument/SB900/Enrolled>.

¹⁹ Learn more at: <https://www.tn.gov/assets/entities/hcfa/attachments/HistOfAPCD.pdf>.

National Transparency Climate *(continued)*

VIRGINIA: The state's APCD is unique in that it was established through legislative mandate, but submissions by payers are voluntary. Virginia's original legislation was introduced as a mandatory bill; however, this resulted in some resistance from the health insurance industry within the state. Examples of voluntary programs outside of Virginia demonstrated the potential for a successful voluntary system, which Virginia stakeholders embraced. Even so, there have been challenges in getting submissions of data from all carriers. The legislation tasks Virginia Health Information, a nonprofit, with managing the APCD, under the authority of the Virginia Department of Health.

RECENT LEGISLATION

In 2015, a number of states (Arkansas, Nebraska, New Mexico, and Washington) proposed APCD legislation with a focus on transparency. Two states, Arkansas and Washington, passed legislation in 2015. Arkansas began implementation of voluntary submission of data to the APCD in 2014 as part of a rate review grant from the Centers for Medicare & Medicaid Services' Center for Consumer Information and Insurance Oversight. The legislation in 2015 (S.B. 956)²⁰ required data submission and more formally cemented the need for consumer transparency. Reasons for passage cited in the bill include:

- **WHEREAS**, Arkansas has consistently received failing grades from independent national organizations that rate states' healthcare quality and price transparency laws;
- **WHEREAS**, Arkansans face a challenge finding reliable, consumer-friendly information on healthcare utilization, quality, and pricing;
- **WHEREAS**, greater transparency of healthcare utilization, quality, and price information leads to more informed, engaged, activated consumers;
- **WHEREAS**, Arkansas has taken significant steps to advance system-wide payment reform, and optimizing the state's efforts requires transforming our healthcare system into a more transparent, more informed, consumer-driven enterprise;
- **WHEREAS**, information about healthcare utilization, quality, and pricing allows policymakers to evaluate health programs and monitor the success and efficiency of efforts to enhance access, reduce healthcare costs, and improve both healthcare quality and population health;
- **WHEREAS**, the availability and integration of healthcare information for legitimate research purposes to qualified researchers supports the pursuits of the state's academic


²⁰ Learn more at: <http://www.arkleg.state.ar.us/Bills/2015/Public/SB956.pdf>.

National Transparency Climate *(continued)*

institutions and the continued study of the evolving landscape of the state's health and healthcare system;

- **WHEREAS**, comparative healthcare information supports efforts to design targeted quality-improvement initiatives and to compare provider performance with that of other provider peers;
- **WHEREAS**, other states have learned the value of integrating healthcare data and transforming it into useful information to the benefit of their citizens while protecting the privacy rights of all individuals;
- **WHEREAS**, demands for information to support program evaluation and healthcare reform and its impact on consumers, businesses, and the state constitute an emergency.”

Washington, which has an existing voluntary database for consumer report cards, passed legislation in 2015 that requires mandated claims data collection (S.B. 5084). The current voluntary database was developed by the Washington Health Alliance²¹ (formerly known as the Puget Sound Health Alliance), and was the combined effort of employers and payers. The database does not, however, contain financial information, such as claim paid amounts. Similar to the Arkansas bill, the primary focus of Washington's 2015 legislation was also transparency:

 The office shall establish a statewide all-payer health care claims database to support transparent public reporting of healthcare information. The database must improve transparency to: Assist patients, providers, and hospitals to make informed choices about care; enable providers, hospitals, and communities to improve by benchmarking their performance against that of others by focusing on best practices; enable purchasers to identify value, build expectations into their purchasing strategy, and reward improvements over time; and promote competition based on quality and cost. The database must systematically collect all medical claims and pharmacy claims from private and public payers, with data from all settings of care that permit the systematic analysis of health care delivery.”²²

Based upon discussions the APCD Council has had with states, it is expected that additional states will propose legislation to implement APCDs in 2016.

²¹ Learn more at: www.wahealthalliance.org.

²² Learn more at: <http://lawfilesexternal.wa.gov/biennium/2015-16/Pdf/Bills/Session%20Laws/Senate/5084-S.SL.pdf>.

Key Findings

The seven key findings in this report are the result of the authors’ synthesis of the stakeholder and state interviews. Although the findings are individually reported, they are often interrelated.

Reliable and trusted price and quality data for consumers are scarce. Similar to other states, New York consumers have few data sources available to them to help navigate the purchase of health insurance, and then navigate the health care system once they have obtained coverage. No single source of reliable and trusted data sources was cited by the stakeholders interviewed. Consumers are looking for information regarding:

• Provider networks	• Provider procedure price
• Formularies	• Provider quality
• Insurance product value	• Provider value

Some of this information is available via the Marketplace, but the Marketplace covers a relatively small proportion of New Yorkers. Some of this information is provided directly by payers, but individual payers have slices of different markets; thereby, they are unable to show provider quality, price, and value information broadly. Some of this information is shown by providers (e.g., hospitals), but different payer-provider contracts result in different pricing (depending on what type of coverage the consumer has), cover a limited set of hospital services, and are not universally available.

Colorado Statute Creates Broad Authority

The Colorado APCD was designed “for the purpose of facilitating the reporting of health care and health quality data that results in transparent and public reporting of safety, quality, cost, and efficiency information at all levels of health care.”

To adequately create a complete picture of quality, price, and value, the New York APD is the primary source of price and utilization data that will be comprehensive across payers and geographies. Many of the interviewees stated that the State has a key role in developing and providing consumers with these data, if only to provide continued pressure on the system to become more transparent.

Pricing data versus charge data are required for true transparency. New York has collected certain medical services via the SPARCS database since 1979. SPARCS contains charge information for procedures in the database. Charge information is considered the list

Key Findings *(continued)*

price for a procedure and is limited in its usefulness given that payer-provider contracts do not historically reimburse providers for charges. Individual payers typically negotiate rates based on a per diem or discounts off of charges, or develop fee schedules that are often indexed to Medicare DRG payments. As one provider interviewed aptly stated, “Charge information is yesterday’s news.”

Massachusetts Statute Focuses on Price

“The center [CHIA] shall make available actual costs and prices of health care services, as supplied by each provider, to the general public in a conspicuous manner on the consumer health information website.”

As is the case for other APCDs, the New York APD proposes not only to collect charges, but also the payment amount actually reimbursed from the payer to the provider, based on their negotiated, contractual rates (known as the paid amount). Deep concern has been raised to date by New York’s payers and some of its providers regarding the collection and release of these paid amounts. These two stakeholders view this contractual pricing information as proprietary, and they have raised anti-trust concerns to the State. Other stakeholders (e.g., consumers, employers, researchers) have stated that the paid amount is most relevant and required for true system transparency. One researcher stated, “The insurance companies don’t want this information out there,” whereas a leading consumer group’s sentiments were recorded as “I am very unsympathetic to the industry about payment information.”

APCD models and consumer price transparency tools are in states such as New Hampshire and Maine, both of which have developed consumer websites for understanding provider and payer pricing. To provide a middle ground to counter concerns about disclosing negotiated rates, New Hampshire’s website (www.nhhealthcost.org) uses an episodic services methodology that bundles multiple prices so that individual procedure code pricing is not revealed. This approach enables consumers to understand price variation among providers, without creating anti-trust concerns. One hospital provider interviewed for this report stated, “bundled payments by episode would be a home run,” as bundled payments would help protect payer-provider contracts of individual procedure code pricing while still providing meaningful information to the consumer.

Transparency is more complex than price shopping. The stakeholders interviewed stated that to meet New York’s transparency needs, any systems or information created for consumers would need to be: factual, credible, timely, integrated across payers and provider networks, objective, and clear.

As previously shown in **Figure 1**, consumers need information both at the point of purchasing an insurance product and when they are accessing benefits and provider services. Interview

Key Findings (continued)

participants stated that the information available currently does not help consumers understand two different, key points of value (on or off the Marketplace):

- The value of the benefit packages offered among carriers, or which plan benefits ensure access to high-quality, high-value care.
- Provider value, or which providers that patients wish to access have the best outcomes at the lowest price.

Benefit package value includes consumer understanding at the point of benefit purchase translated as the ratio of plan premium to benefit package, network coverage, and network quality. In other words, “How do I know that I am getting the best value of benefits and [policy] premium when I purchase a policy?” To date, this has been very difficult for consumers to quantify and understand. Some consumers purchase directly from the health benefit exchange, whereas others are selecting from plans that their employers offer. One example of a state working on this issue is New Hampshire, which has created a benefit richness index as part of its annual supplemental insurance market report²³ (Figure 3). The intent is to provide information based upon product and market size to assist employers with understanding

FIGURE 3: New Hampshire Benefit Richness Comparison

PLAN TYPE	MARKET CATEGORY	Self-Insured			Fully Insured		
		MEMBERS	AVG PREMIUM	BENEFIT RICHNESS	MEMBERS	AVG PREMIUM	BENEFIT RICHNESS
HMO	Large Group	92,613	\$471	0.92	62,249	\$450	0.82
	Small Group	169	\$521	0.90	69,533	\$427	0.80
	Non-Group	No membership Reported			4,762	\$206	0.89
POS	Large Group	40,982	\$489	0.94	3,489	\$483	0.81
	Small Group	4	\$556	0.92	1,318	\$431	0.72
	Non-Group	No membership Reported			No membership Reported		
PPO	Large Group	105,146	\$430	0.85	32,506	\$429	0.81
	Small Group	363	\$484	0.86	15,013	\$442	0.78
	Non-Group	No membership Reported			34,606	\$302	0.72
EPO	Large Group	No membership Reported			5,817	\$483	0.81
	Small Group				5,091	\$431	0.72
	Non-Group				4	\$559	0.70
Indemnity	Large Group	4,607	\$549	1.01	768	\$429	0.83
	Small Group	62	\$508	0.90	No membership Reported		
	Non-Group	No membership Reported			1,473	\$191	0.62
TOTAL MEMBERS		243,945	\$458.05	0.90	236,630	\$410.51	0.79

²³ Learn more at: <http://nhhealthcost.nh.gov/health-costs-employers>.

Key Findings *(continued)*

benefit package value. This information is derived from a combination of New Hampshire's APCD and supplemental carrier reporting.

In terms of provider value at the point of accessing benefits and services, the notion of developing a provider value equation was suggested by a majority of those interviewed for this report. "If I could only get a quick list of the top 10 providers in a specific geography who perform 'XX' procedure at the highest quality and lowest price" was a common refrain. The interviewees did not deem it adequate to show only pricing or quality information—both need to be available to consumers in an easily digestible format.

Finally, one employer interviewee stated, "We need to leverage providers to drive quality and cost. This [APD] effort is not all about the consumer shouldering transparency." The employer was reflecting on the burdens currently placed on consumers from a cost-sharing perspective, as well as when navigating the health system. This point was further echoed by several consumer advocates and during one of the RHIO interviews. These stakeholders believe that data need to be made available very broadly to consumers, providers, and policymakers so as to impact quality, cost, and utilization.

The State's vision, goals, and timeline for the APD are unclear to stakeholders. During the stakeholder interviews, there was an almost universal lack of clarity of the vision, goals, and timeline for the APD. Most stakeholders understood that claims data would be collected—and the majority expected information for consumers and researchers to be provided—but nearly all cited a lack of basic understanding of the APD mission. When probed more deeply, some interviewees who had been on an original APD steering committee for external

Statute Examples with a Clear Purpose

VIRGINIA: The Virginia All-Payer Claims Database is hereby created to facilitate data-driven, evidence-based improvements in access, quality, and cost of health care and to promote and improve the public health through the understanding of health care expenditure patterns and operation and performance of the health care system.

OREGON: The Administrator of the Office for Oregon Health Policy and Research shall establish and maintain a program that requires reporting entities to report health care data for the following purposes:

- Determining the maximum capacity and distribution of existing resources allocated to health care.
- Identifying the demands for health care.
- Allowing health care policymakers to make informed choices.
- Evaluating the effectiveness of intervention programs in improving health outcomes.
- Comparing the costs and effectiveness of various treatment settings and approaches.
- Providing information to consumers and purchasers of health care.
- Improving the quality and affordability of health care and health care coverage.
- Assisting the administrator in furthering the health policies expressed by the Legislative Assembly in ORS 442.025.
- Evaluating health disparities, including but not limited to disparities related to race and ethnicity.

Key Findings *(continued)*

stakeholders stated that the project had run out of steam during a management transition, whereas others representing consumer interests had not been contacted by the State to participate. The industry (providers and payers) was the primary exception as its government affairs staff has been attending meetings in Albany, as well as had an understanding of APCD development in other nearby states (e.g., Connecticut and Massachusetts).

This lack of clarity by the stakeholders is an opportunity for the State to seize. Without solid stakeholder knowledge and support, the ability to develop an APD system and program is hampered. At the most basic level, the feelings of disconnectedness and uncertainty in the stakeholder community can be politically destructive and self-undermining to the work that the State is trying to accomplish.

The New York APD is viewed as a public utility with unclear governance. According to the majority of New York’s APD stakeholders interviewed, the APD is seen as a public utility model designed to fulfill a social contract between the State and New York’s citizens, whose data reside in the APD. One researcher stated, “The State can be the honest broker [of this information].”

This social contract begins with the fact that the APD is funded with public tax dollars, both State and federal; therefore, the stakeholders believe the data should be used to benefit the public.

Virginia APCD as a Benefactor of Public Good

“The [Virginia] General Assembly finds that the establishment of effective health care data analysis and reporting initiatives is essential to improving the quality and efficiency of health care, fostering competition among health care providers, and increasing consumer choice with regard to health care services in the Commonwealth, and that accurate and valuable health care data can best be identified by representatives of state government and the consumer, provider, insurance, and business communities.”

Additionally, the stakeholders believe that the State has a responsibility to be the one to guarantee the privacy of individuals’ data held within the system—with privilege comes responsibility.

To deliver on the implied social contract, the interviewees stated that New York, at a minimum, needs to focus on reporting on the following four areas:

• Population health metrics	• Quality of care
• The pricing of services	• Research to support and drive public policy

The New York stakeholder interviews also revealed a lack of understanding of the APD program’s governance structure. Most stakeholders believed it to be housed by the NYSDOH, whereas others also were aware that NYSDFS had APD interests as well, such as rate review

Key Findings *(continued)*

audits. About half were aware of the HIT workgroup, but most that were aware did not know if the HIT workgroup had any management or authority functions for the APD. The other component of governance discussed was data release management. Again, there was no clear understanding of how the APD data release process will be managed, but many stakeholders recommended that it mimic the release process of the SPARCS program.

Based upon work conducted by the APCD Council with other states,²⁴ there are typically seven components of a governance structure for New York to consider:

- APCD legislation
- Governing body and oversight
- Scope of the data collection effort
- Privacy and confidentiality
- General funding considerations
- Reporting requirements
- Interagency agreements

A broad consumer strategy across State agencies will require concerted effort and coordination. The majority of the stakeholders, as well as the APCD states interviewed, identified the need for the development of a broad consumer strategy across State agencies—health (NYSDOH), insurance (NYSDFS), employees (NYSDCS), Medicaid, and the Marketplace (NY State of Health). Each of these agencies impacts consumers in various ways, including population health improvement efforts, health reform, insurance coverage, and quality of care. Each of these agencies desires access to the APD to support research, State policy initiatives, consumer transparency tools, system performance, rate review, clinical operations, the Triple Aim, and other efforts. One interviewee stated that there is “a lot of momentum and potential for New York agencies to come together.”

To support these various internal State needs, a broad consumer strategy needs to be developed to coordinate APD resources and uses across State agencies. This will begin with the NYSDOH’s internal coordination across divisions (e.g., SPARCS, SHIN-NY, APD), but also will require programmatic coordination (e.g., DSRIP, SHIP, Medicaid, RHIOs/Qualified Entity, the Marketplace, rate review). To date, such a formalized mechanism has not been developed.

²⁴ All-Payer Claims Database Development Manual: Establishing a Foundation for Health Care Transparency and Informed Decision Making, <http://www.apcdouncil.org/manual>, accessed September 2015.

Key Findings *(continued)*

Fiscal and programmatic sustainability likely will be an ongoing challenge. Although the development of an APD has many clear benefits for public policy, research, employers, and consumers, benefits for providers and payers have sometimes been less clear for states with APCDs. From a payer perspective, the development of an APCD with the requirement to submit data is essentially an unfunded mandate. From a provider perspective, there typically are concerns regarding accuracy of information when reported at a provider level. Providers and payers have additional concerns about data release, particularly around disclosure of payment information vis-a-vis potential anti-trust concerns.²⁵ Both payers and providers typically are concerned with the public release of contractual payment information.

This lack of clarity of value from providers and payers has led to sustainability challenges in some other states. Some of these challenges have been programmatic, such as the overall need for the development of a claims database or the need to collect self-funded commercial claims for ERISA employers, whereas others have been fiscal. To better build broad support and reduce challenges to either programmatic or fiscal sustainability, New York will need to clearly define to stakeholders, legislators, and the Governor's office the use cases that the APD will support. Additionally, the ongoing programmatic investment will need to be defined along with a sustainability strategy.

Some parties interviewed for this report stated that New York's "best chance of initial success" would be to focus early data release efforts on projects targeting Medicaid, State employees, the qualified health plans, and existing State programs, such as RHIOs/Qualified Entities and DSRIP. There are utilization, cost, population health, and other studies that will benefit the operations, policies, and outcomes of these publicly funded programs that have already seen significant State investment. One researcher aptly stated that the "State needs political resolve to see this through."

²⁵ All-Payer Claims Database Development Manual: Establishing a Foundation for Health Care Transparency and Informed Decision Making, <http://www.apcdouncil.org/manual>, accessed September 2015.

Recommendations

Five recommendations were developed by the authors after synthesizing the stakeholder and State interviews. The recommendations have been shared directly with NYSHHealth and the NYSDOH.

Develop a phased approach to APD data release based upon use cases. This approach will help define the program, as well as manage stakeholder expectations. **Figure 4** is a synopsis of use case requirements gleaned from the stakeholder interview process, with five core areas represented: research, support for State policy initiatives, transparency tools, system performance, and clinical operations. The first three columns of **Figure 4** represent the areas of recommended initial data release.

It is recommended that the State begin its data release process by providing data to researchers, which will accomplish two objectives. First, the data will be placed in trusted, third-party hands of researchers who have experience analyzing claims data and will demonstrate uses of the data. Researchers will produce findings that will be in the public domain and may inform public policy. Releasing to researchers has the added benefit of leveraging external funds for analysis. Second, these researchers can become an important part of the data quality program—finding issues with the data and reporting back to the APD program, which will communicate with the data

FIGURE 4: New York Use Cases Defined by Stakeholder Interviews

PHASE 1			FUTURE	
RESEARCH	SUPPORT FOR STATE POLICY INITIATIVES	TRANSPARENCY TOOLS	SYSTEM PERFORMANCE	CLINICAL OPERATIONS
<ul style="list-style-type: none"> • Population Health • Prevalence Measures • Utilization • Payment • Cost Drivers • Econometric • System Performance • Simulation Modeling • Geographical • Evaluate Translational Research Efforts 	<ul style="list-style-type: none"> • DSRIP • PHIP • NY-SHIP • Medicaid • RHIOs/QEs • Rate Review • Rate Setting • Policy Development 	<ul style="list-style-type: none"> • Price • Quality • Premium • Networks • Formulary • Value • PHR • Embedded Within Insurance Exchange • System Access and Navigation 	<ul style="list-style-type: none"> • Provider • Network • Payer • Identify Centers of Excellence • Outcomes • Resource Disparity • Gaps of Care / Effective Care • Delivery System Redesign • Payment Model Design 	<ul style="list-style-type: none"> • Data for Practices • Risk Adjustment • Leakage / Referral Analysis • ACO Performance • Clinical Data (RHIOs)

Recommendations (continued)

submitters. More eyes on the data early on in the APD program release process should lead to higher-quality data. Several researchers interviewed for this project would like to have a more in-depth relationship with New York's APD program to leverage resources, engage more stakeholders, produce information, and inform future research.

In addition to researchers, the State should be able to release data simultaneously to support existing State policy initiatives. There are current needs for claims data to support DSRIP, PHIP, SHIP, Medicaid, RHIOs/Qualified Entities, and other State programs. This in turn would allow multiple State agencies (e.g., NSYDOH, NYSDFS, NYSDCS) to develop data-driven policy initiatives and ideally coordinate across agencies for information sharing and data quality purposes.

Once the researchers and State agencies have worked with the data and developed a data quality program, the development of transparency tools is a likely next area of focus. This will require the development of a master provider index for provider comparison tools. It is expected that these tools will be made available on the Marketplace and to consumers shopping for services.

Figure 4 also delineates system performance and clinical operations as areas for future APD development work. The system performance work likely will be conducted by the State, researchers, payers, carriers, and other stakeholders. The clinical operations use cases likely will require policy development regarding data linkage of patient-identifiable data, and potentially opt-in/opt-out policies to protect such data. This is considered a very promising area for APD development by other states with existing APCDs.

Develop price transparency tools. Ultimately, the development of price transparency tools will serve New York consumers and taxpayers. Information about health plans, provider networks, utilization, and charge-to-price ratios should be included.

The State is the only entity, public or private, that can construct a database with the breadth of data across payers as outlined earlier in this report. As one interviewee stated, "the attraction of the APD is a single source of data and only the government can do this." For other state APCDs, this single source of data includes medical, behavioral, pharmacy, and dental claims across commercial and public payers. Today, New York's SPARCS data set is limited to hospital claims and only contains charge data, which as discussed elsewhere in this report is very limited for price comparison purposes.

Carriers will continue to promote their own price transparency tools, as will third parties, such as FAIR Health²⁶ or the Health Care Cost Institute²⁷, but these entities often either do not collect all claims, do not include all payers, or cannot release claims (or paid amounts) for all payers and by provider because of contractual limitations. This will have an impact on the usefulness

²⁶ Learn more at: <http://www.fairhealth.org/>.

²⁷ Learn more at: <http://www.healthcostinstitute.org/>.

Recommendations (continued)

of the data they report, based on limits of population, geography, or financial information available. For New York to develop a transparency website, such as the top-ranked NH HealthCost website,²⁸ all claims from all payers are required.

The majority of the stakeholders interviewed believe that the State has a responsibility to develop price transparency tools for the New York consumer marketplace. There are many challenges with the data, including the development of a master provider index. Additionally—given there are more than a million uninsured New Yorkers—providing transparency across providers (both charges and payments) can give the uninsured a typical price paid by those with insurance from which to negotiate care they can afford. Having said this, not all stakeholders believe the State would be able to implement such tools expediently.

The authors acknowledge that a price transparency site developed by New York may not be able to provide consumers with the precise out-of-pocket costs that reflect deductibles and other consumer liabilities, as this information is most accurately accessed from the consumer's health plan. However, multiple states the authors spoke with in the development of this report responded that states have a responsibility to deliver this information, if only to help keep pressure on the industry regarding price and quality transparency. In 2009, the Center for Studying Health System Change (CSHSC) examined the impact of price transparency after New Hampshire launched its consumer transparency website in 2007.²⁹ CSHSC's report noted "some observers suggested that HealthCost—along with other state price transparency initiatives—has helped to focus employer and policymaker attention on provider price differences and has caused some hospitals to moderate their demands for rate increases."

Include self-funded data sources in the APD. In most states, New York included, between 30-50% of the commercially insured population falls under ERISA benefit plan arrangements. These plans typically are administered by health plans or third-party administrators. For the New York APD to truly be an all-payer database, the inclusion of these self-funded data sources in the data collection is imperative. The majority of states with APCDs do collect these data. Colorado's legislation originally did not allow for the collection in 2010; however, with employer support, a rule change has been requested in 2015.³⁰

Cases have been brought before federal courts in Maine and Vermont in an attempt to remove the states' authority to collect self-funded data.³¹ The federal district court in Maine found in favor of the state's authority. In Vermont, a challenge to its collection of self-funded claims has risen to the

²⁸ Catalyst for Payment Reform, "Report Card on State Price Transparency Laws," http://www.hci3.org/sites/default/files/files/2015_Report_PriceTransLaws_06.pdf, accessed September 2015.

²⁹ Learn more at: <http://www.hschange.com/CONTENT/1095/>.

³⁰ Learn more at: <http://www.civhc.org/getmedia/1d504402-8acb-4fc6-a812-a7c49007960f/Self-Funded-FAQs.pdf.aspx/>.

³¹ Maine: *Patient Advocates, LLC v. Prysunka*, No. 03-118-P-H, 2004 WL 114980. Vermont: *Liberty Mut. Ins. Co. v. Kimbell*, 2012 WL 5471225 (D. Vt. Nov. 9, 2012) and *Liberty Mut. Ins. Co. v. Donegan*, 746 F.3d 497 (2d Cir. 2014).

Recommendations (continued)

U.S. Supreme Court. While Vermont waits on the Supreme Court decision, only one third-party administrator data submission currently is being withheld from the Vermont APCD, but all other self-funded submissions are being made. In September 2015, the New York State Attorney General (on behalf of New York, 16 other states, and the District of Columbia) filed a brief with the Supreme Court as *amicae curie* in support of the Vermont petitioner, the Green Mountain Care Board.³² New York and other states remain committed to the right to collect these data.

Given the historical collection of other states, the need to include self-funded data to create an APD, and the support of New York’s Attorney General to collect such data, the authors of this report recommend that the State move ahead with its proposal to include data from self-funded plans in the New York APD data collection regulations when they are released.

Develop a stakeholder engagement and communications process regarding the APD startup functions. To develop stronger stakeholder understanding, engagement, and support, it is recommended that New York develop an engagement and communications process regarding the APD startup functions currently under development. Stakeholders need to understand the programmatic and policy governance structures to bring a more unified, supportive group of stakeholders to the table. The previously developed APD steering committee should be re-structured to create a mechanism for stakeholder input and support.

Moving forward, New York, at a minimum, should address the following two areas:

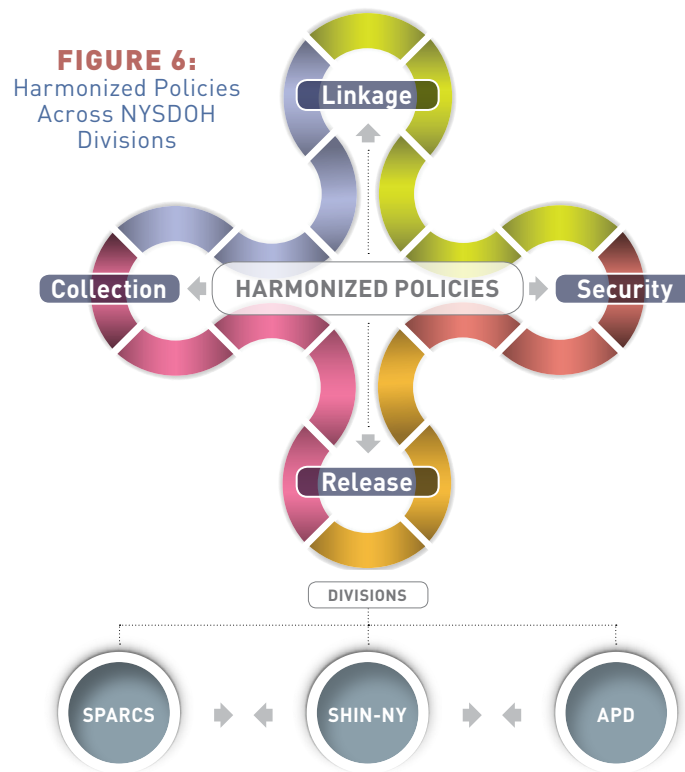
- **The finalization and articulation of the APD governance structure, both programmatically and policywise.** Programmatically, linkages between NSYDOH, NYSDFS, Medicaid, and NYSDCS need to be spelled out. As shown in **Figure 5**, New York needs to develop, finalize, and publish policies that support the collection, protection, and release of the data.



³² Learn more at: <http://www.scotusblog.com/wp-content/uploads/2015/09/VHCURES-Amicus-Brief-of-New-York-et-al.pdf>.

Recommendations (continued)

- **A formalized stakeholder communications strategy.** It is recommended that the State develop a formalized stakeholder communications strategy, primarily to facilitate policy development and rollout. This would minimally include more regular communications via the existing listserv, public website updates, and updates to the HIT workgroup. Developing a media component would be another way to leverage communications and build a broader stakeholder list. Existing stakeholders also should be engaged so that their communications vehicles speak of the APD development.



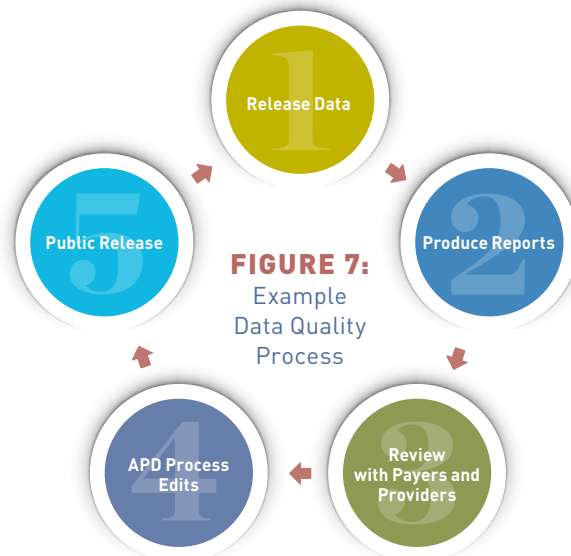
As shown in **Figure 6**, the harmonization of data linkage, release, and security policies across the SPARCS, APD, and SHIN-NY programs has been suggested by stakeholders as important to making the APD operational while maximizing historical programmatic and operational experience.

Formalize an APD data quality program. Universally, data quality was considered to be an important component of New York’s APD program development. Data quality was seen as paramount for both trust and usefulness, with continuous feedback resulting in more accurate information over the long term.

Recommendations (continued)

Similar to **Figure 7**, it is recommended that New York create a process to include input and review of data by submitters (payers) and those being reported on (providers). Other states have indicated that review of reports by payers and providers has been key to data quality. It is recommended that the State develop and formalize such a program as part of its startup operations.

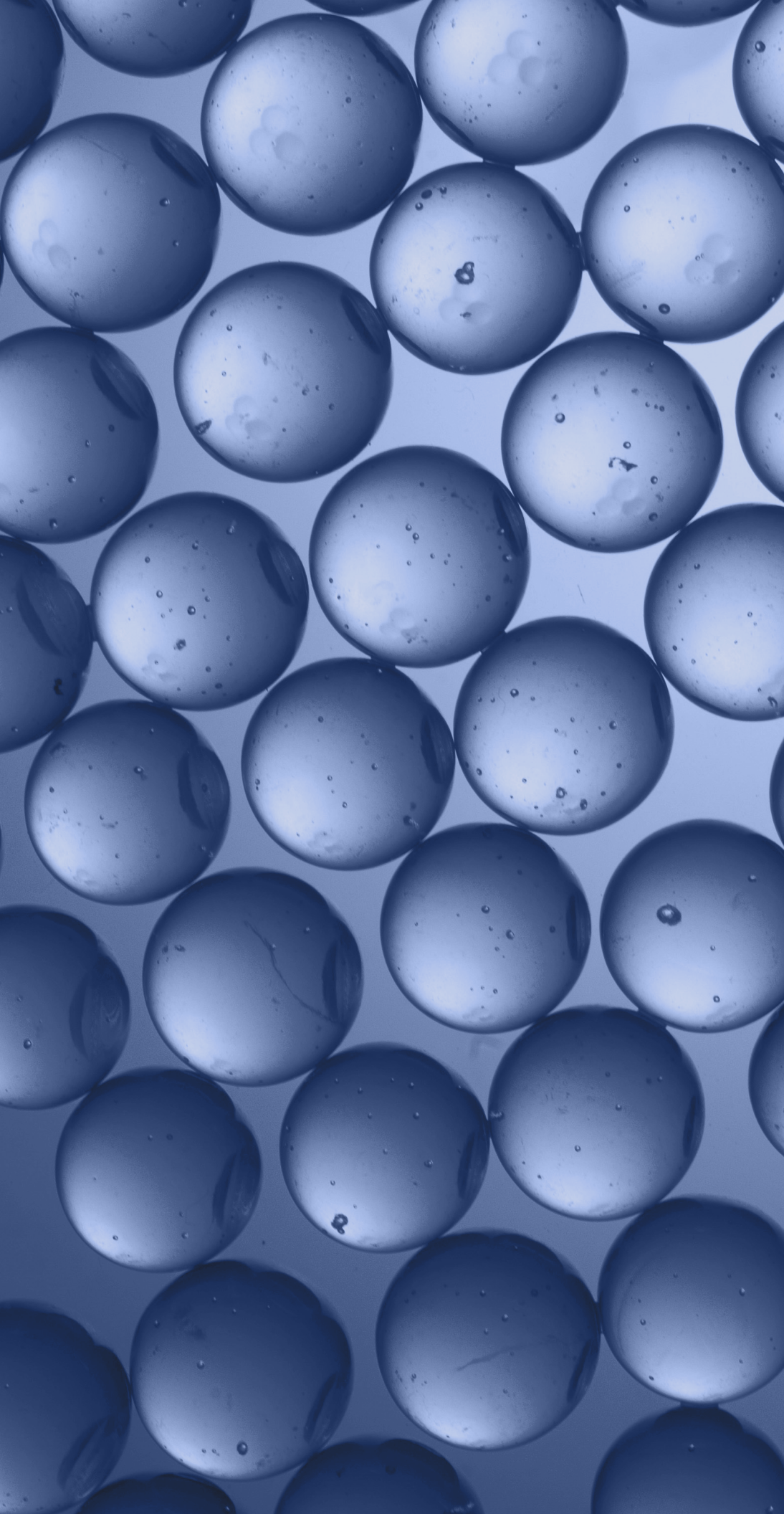
Another way to increase data quality would be to include researchers very early on in the data release and data quality processes. Researchers who have worked with claims data sets previously will possess the skills required to assist the State's APD team in carrying out the data quality plan. Several researchers interviewed for this project cited a desire for tighter integration with the State's APD program, and this is one possible way to accomplish that objective.



CONCLUSION

The New York APD has tremendous potential to be a long-term asset to New York and its citizens. There are potential benefits to researchers, employers, State government, payers, and providers, similar to those seen in other states with APCDs. To attain those benefits, New York will need to solidify its APD stakeholder base, use cases, governance structure, communications plan, and funding streams.

New York also will need to develop a consumer strategy, likely phased, that will encompass the needs of consumers as they both purchase health benefits and use them. This will be a heavy lift across multiple State departments and external stakeholder groups, but New York has a solid foundation for this work through its long-standing data efforts.



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