

All-Payer Claims Database

DEVELOPMENT MANUAL

Establishing a Foundation for Health Care Transparency and Informed Decision Making

MAR 2015

APCD Council

The APCD Council is convened and coordinated by the Institute for Health Policy and Practice at the University of New Hampshire and the National Association of Health Data Organizations.

Acknowledgement

This APCD Manual was created by the APCD Council with assistance and support from the Gary and Mary West Health Policy Center.

About the West Health Policy Center

The Gary and Mary West Health Policy Center is a nonprofit, non-partisan resource in Washington, D.C. providing education, expertise and policy proposals to transform the American healthcare experience. We're wholly funded by philanthropists Gary and Mary West as part of West Health, four organizations with a common mission—pioneering new and smarter technologies, policies and practices, to make high-quality healthcare more accessible at a lower cost to all Americans.

Along with the Policy Center, West Health includes the Gary and Mary West Health Institute, a nonprofit medical research organization working to create new, more effective ways of delivering care; and the for-profit Gary and Mary West Health Investment Fund and West Health Incubator, providing investments and expertise to businesses that share our mission.

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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.

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Executive Summary

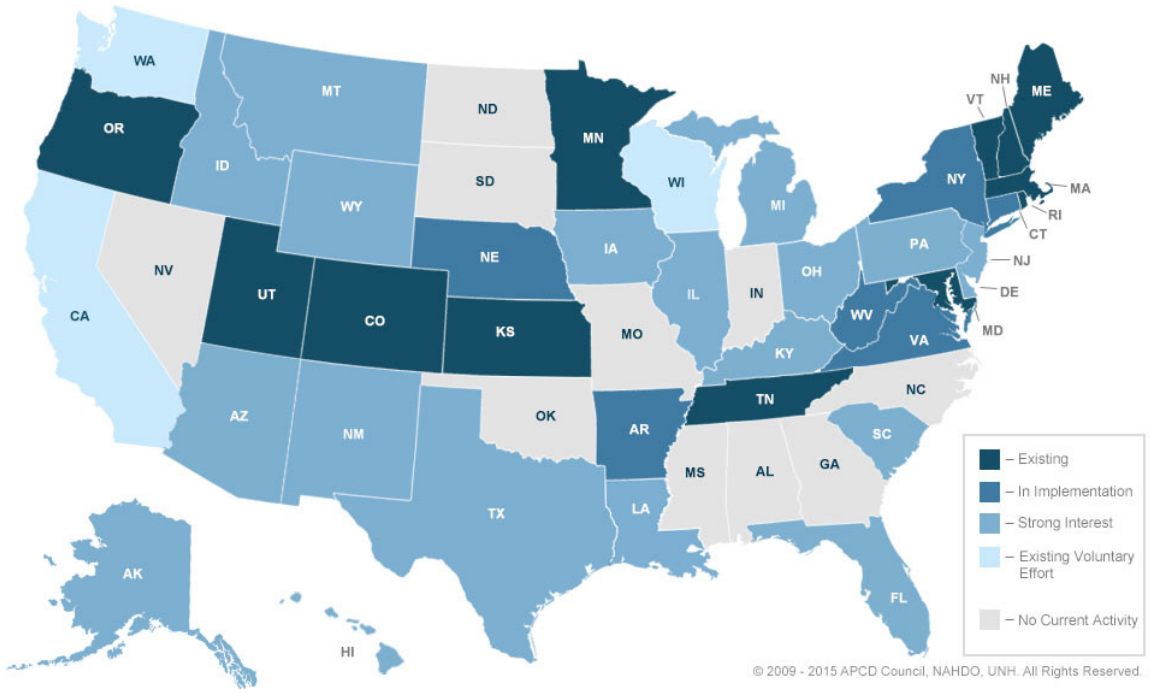
States are discovering that transforming health care requires a series of new regulatory and market approaches. While states vary in these approaches, most states recognize the vital role multi-payer health data and information systems will play in health care and payment reforms. To meet these needs, an ever-growing number of states are implementing All-Payer Claims Databases (APCDs), aggregating claims and administrative data from public and private payers statewide. States are developing APCD reporting systems to fill critical information gaps, promote health care transparency initiatives, and provide actionable information for their stakeholders.

Statewide APCDs:

Databases, typically created by a 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.

The APCD Council is a nationwide 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 maintains a map of state progress on APCD development. As of February 2015, there are 12 states with existing APCDs, 6 in implementation, 3 existing voluntary efforts, and many other states with interest in developing an APCD (Figure 1).

FIGURE 1: STATE APCD DEVELOPMENT, FEBRUARY 2015



APCDs are complex data systems, and states seek guidance for recommended approaches and best practice solutions to common technical issues. This manual is designed to provide a summary of the many years of collective learning into a single source of information to support APCD development. The APCD Council has created a framework (Figure 2) as an overall guide to structure state APCD development; this manual provides the details supporting the framework. The framework includes five (5) major aspects to APCD development:

- *Engagement*
- *Governance*
- *Funding*
- *Technical Build*
- *Analysis & Application Development*



FIGURE 2:
APCD DEVELOPMENT FRAMEWORK

In addition, the most successful state APCDs recognize that the work does not stop after the initial implementation, and the arrows on the outside of the figure represent that APCD development is a continuous process (discussed in its own section in the manual).

There are key findings in each of the five areas represented in the APCD development framework.

Engagement

A foundational step in the development of an APCD is articulating and communicating the purpose of the APCD – the rationale for why the APCD is needed and what is to be accomplished by creating it. Defining this purpose should be done through a robust stakeholder engagement process. The stakeholder group, representing a variety of interests in APCDs, can include:

- *Policy makers*
- *Payers*
- *Health care providers*
- *Employers and employer coalitions*
- *State agencies*
- *Consumers*
- *Researchers*
- *Health Information Exchange (HIE) and Health Insurance Exchange (HIX) systems.*

Successful APCD development in an individual state will require comprehensive engagement of these varied partners, resulting in a shared vision. By defining the vision for the APCD system, the key contributors to it (e.g., resources, data, and infrastructure), and the intended use cases for the data, states can cultivate strong community to support APCD development.

Governance

Governance covers a broad array of aspects of the APCD, including authorizing legislation, defining rules and regulations to guide operations, designating of an oversight entity (or entities) for the APCD, and composing a governance structure (e.g., a board or commission) providing policy guidance and

oversight. These components form the foundational structure of the APCD and have bearing on all aspects of the technical build and use of the APCD. The components of a governance structure typically address:

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

While the parameters of governance are similar state-to-state, the specific components of governance vary to meet the needs of the individual state. The final governance parameters (in legislation, rules, and policies) will reflect the state's intended use of the data, political environment, oversight of the system, and assurances for privacy and data use. Governance policies can drive, or limit, the functionality of a state's APCD system. For example, Minnesota's original legislation restricted access and use of APCD data to the state health department. Conversely, Colorado's legislation mandated public reporting of provider-level cost, price, and quality comparative reports for common medical procedures to enable consumer decisions and choice.

Funding

APCD funding is a key consideration for APCD development, both at the initial development phase and as the system evolves. Costs for APCD planning, implementation, and maintenance vary by state. Funding considerations involve all aspects of system development and operation and should include:

- *Scope: State population (e.g., number of covered lives) and insurance coverage patterns (e.g., the types of health insurance products in place for the population)*
- *Infrastructure needs: Location of the agency where the APCD is to be housed (e.g., insurance department, health department, or other type of arrangement, such as a state-sponsored private entity)*
- *Data use and access: Planned users and uses for the APCD and associated costs of data release (e.g., if researcher access is planned or that public websites will be developed).*

All APCD programs will benefit from diversifying revenue sources as a strategy for sustaining their systems for the long-term (i.e., future development and ongoing maintenance). Thus, APCD initiatives are actively seeking partnerships with other state agencies, such as Medicaid agencies, insurance departments, and health departments to leverage funding and align technical solutions. For example, in Colorado, with a mandate for public reporting and broad user access, the APCD agency is leveraging inter-agency partnerships for funding to offset the costs of data release. Many state APCD programs are working closely with other state agencies to use APCD data to meet the needs for federal grant programs, and using those grants to improve APCD data collection and/or analysis.

Technical Build

The technical build phase of APCD development results in the operational and quality assurance protocols for receiving and processing the data that will be used for analytics and applications. There are several determinants to understanding the scope of work necessary to support the APCD technical build, including:

- *Analysis and reporting needs*
- *Volume and size of carriers*
- *Types and sizes of files*
- *Inclusion of public payers*
- *Data submission requirements*
- *Data submission schedule*
- *Data quality requirements*

Defining the data elements for the APCD is a key step in the technical build. Because claims data are generated for billing purposes, the data elements are generally available across payer systems. Uniformity of data submission is important, both for reasons of comparability within and across states, and to reduce the payers' burden to submit data to different states, in different formats. To address these issues there are initiatives with Standards Development Organizations to standardize data reporting formats. Early efforts in standardization have resulted in industry reporting standards that align with both state reporting needs and payer reporting capabilities.

There is growing interest in identifying ways to collect new data elements (e.g., benefit design information) and linking APCDs to other data sets. These innovations in APCD development will likely require new, and often supplemental, approaches to the collection of data in the APCD. New approaches to data privacy for linkages at the individual record-level may also be needed.

Collecting and aggregating claims data files across payers is a complex process, with both technical and political challenges. This complexity has led many states to rely on vendors to build the state APCD operations. The Request for Proposal (RFP) process is an important step in the development of APCDs for many states, and being deliberate and clear in the RFP is important to ensure that the needs for the APCD system are met.

The construction of state APCDs is complex and resource-intensive, warranting careful planning with all stakeholders. The technical build planning process starts with strategic consideration of what the desired outcomes are for analyses and reporting. The existing APCD states can be helpful resources to those states considering building an APCD.

Analysis and Applications Development

Although states vary in their reporting priorities and APCD approaches, the value and sustainability of any APCD system is closely linked to the information it provides to inform consumer, policy, market, and research decision-making.

The development of an analytic plan can help define both the intended use of the APCD for the state, and also with parameters to release data to allow for analysis by other stakeholders. The analytic plan guides the data analytics and release processes, specifically:

- *What information, if any, will be shared*
- *With whom data reports will be shared*
- *When data and reports will be shared*
- *Restrictions to public release and access*
- *In what formats data will be released*

Data reporting and data release are complex activities requiring agencies to address numerous political and technical challenges. States may need release processes, Data Use Agreements (DUA), and review protocols to support their analytic plans. APCDs also often establish a technical advisory, data user, or other group of stakeholders specifically focused on appropriate and effective use of data. These groups assist in the many decisions that must be addressed in order to produce quality analytics and applications.

A comprehensive analytic plan with a transparent and open process for providing data at various levels of detail for key user types is important to assuring that APCD data are used appropriately and safely. States are proving that it is possible to provide cost-effective, useful information to multiple stakeholders while protecting the underlying data.

Feedback Loops and Continuous Engagement

Stakeholder engagement is critical in APCD design, construction, and the production of meaningful information. States that have invested in building strong stakeholder processes have forums to deliberate the many challenges faced during each phase of system development and deployment. As APCD programs and systems mature, stakeholders provide input for enhancements that drive the ultimate value of the information produced.

Key factors to maintaining stakeholder engagement over time include:

- *Inclusiveness*
- *Transparency and open processes*
- *Managing expectations*
- *Clear feedback loops*
- *Data quality assessment and improvement*

Having both a well-defined work plan and communication plan can help guide the state in its work and make that planned work clear to all stakeholders.

Conclusion

This manual is designed to help states develop an APCD by summarizing the major issues and approaches to address them. It is a compilation of experiences and lessons learned across multiple statewide APCD initiatives. The development of an APCD system can be a challenging process; however, states have found a number of common issues during development, and solutions to issues can be consistently applied across states.

States will likely tailor the approach outlined in this manual. The intended uses of the data, the governance structure, the funding sources, and other aspects of the APCD will be developed to meet the needs, capacities, and resources of each state. While there are state-specific differences, there is value in having common attributes of the APCDs, and there are enough similarities between states to be able to share experiences and advice among one another.

The APCD Council would like to thank the Gary and Mary West Health Policy Center for their generous support of the work to develop this manual. In addition, the APCD Council would like to thank the members of the State Advisory Panel; in particular, Kevan Edwards, PhD; Jonathan Mathieu, PhD; Stacey Murdock PhD; and Dian Kahn, MPA, for their in-depth review. Also, the APCD Council would like to acknowledge Patrick Miller, MPH, for his review and edits to several versions of the manual. Finally, the APCD Council would like to thank the many, many state partners whose work has informed this guide.

Introduction

About the APCD Council

In 2007, the Regional All-Payer Healthcare Information Council (RAPHIC) began as a convening organization to bring together several Northeast states that had, or were developing, All-Payer Claims Database (APCD) systems.

Statewide APCDs:

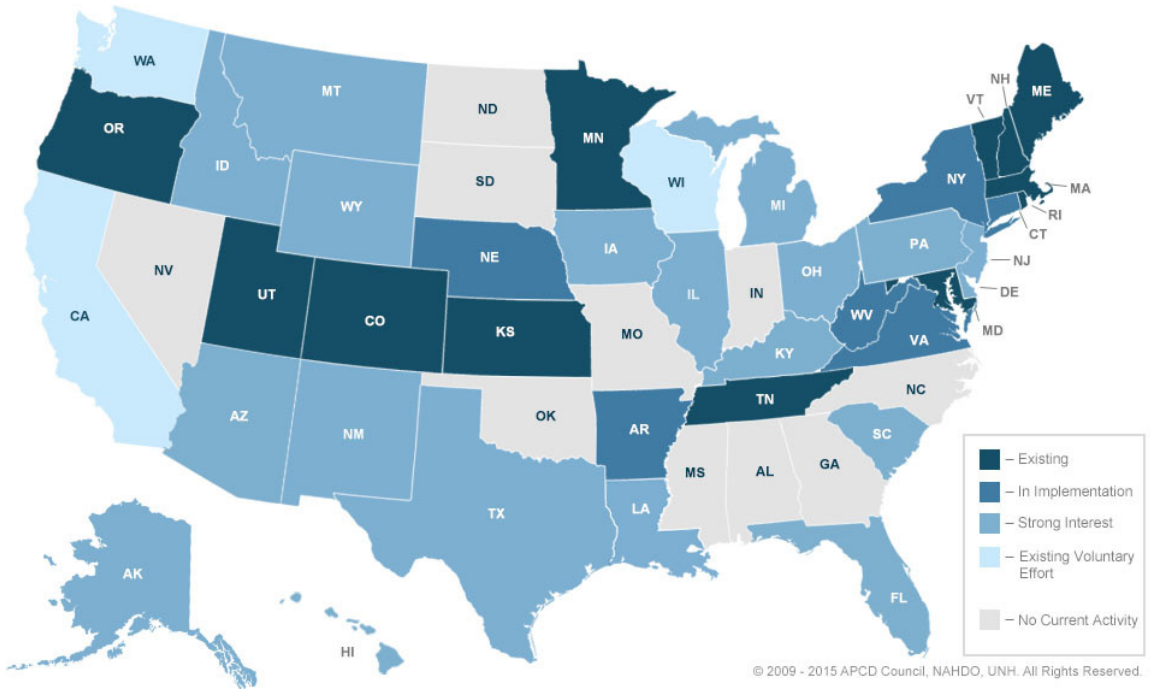
Databases, typically created by a state mandate, that generally include data derived from medical claims, pharmacy claims, eligibility files, provider (physician and facility) files, and dental claims from private and public payers.

The vision for RAPHIC was to support cross-state data harmonization and analytic activities. RAPHIC quickly expanded to include participation from states across the country and a broader set of learning network activities. In 2010, RAPHIC changed its name to the APCD Council to reflect the expanded reach.

In the time since the initial meeting in 2007, the APCD Council has helped states across the country with a variety of activities related to APCD development, including:

- *Stakeholder meetings*
- *Legislation review*
- *Rule development*
- *Vendor selection*
- *Analytics support*
- *Linking states to one another to find common solutions*
- *Leveraging state resources to achieve common objectives*

FIGURE 1: STATE APCD DEVELOPMENT, FEBRUARY 2015



The APCD Council maintains a map of state progress on APCD development. As of February 2015, there are 12 states with existing APCDs, six in implementation, three existing voluntary efforts, and many other states with interest in developing an APCD (Figure 1).

About the ACPD Development Manual

This manual is designed to provide a summary of the many years of collective learning about APCD development into a single source of information. The APCD Council has provided the framework in Figure 2 as an overall guide to state APCD development; this manual follows that structure. The framework includes five (5) major aspects to APCD development, each of which will be discussed in detail in this manual:



FIGURE 2:
APCD DEVELOPMENT FRAMEWORK

- *Engagement*
- *Governance*
- *Funding*
- *Technical Build*
- *Analysis & Application Development*

In addition, the most successful state APCDs recognize that the work does not stop after the initial implementation, and the arrows on the outside of the figure represent that APCD development is a continuous process (discussed in its own section in the manual).

Each section of this manual describes one aspect of the development framework. The sections include a guide and a checklist. The guide portion provides key considerations, current state practices, and recommendations or suggestions for APCD development. The checklist portion provides links to tools and worksheets, which are located in the appendices, for states to use for the various steps in the development process outlined in the manual.

It is important to note that this manual is designed to help states develop an APCD, but that state APCD development experience is unique. The approach to development may be tailored for an individual state. The intended uses of the data, the governance structure, the funding sources, and other aspects of the APCD will be developed to meet the needs, capacities, and resources of each state. However, while there are state-specific differences, there is value in having common attributes of the APCDs, and there are enough similarities between states to be able to share experiences and advice among one another.

SECTION 1:

Engagement

A requirement for successful APCD development is a coordinated engagement strategy. This includes a number of foundational aspects of APCD development, including articulating the goals of the APCD program and identifying the appropriate stakeholder community. This community needs to be engaged in the APCD development effort and must remain engaged in the long-term for the APCD success.

Learning Objectives

- What is the purpose of engagement?
- Which stakeholders need to be engaged?
- What constitutes effective engagement?
- Why is engagement important?

Defining the Vision for the APCD Program

A critical step in developing an APCD is to define the purpose of the program. Carefully defining and articulating the anticipated purpose of the system and uses of the data is an important step in managing expectations for, and avoiding confusion about, the APCD. Statements of purpose generally define the conceptual need for the APCD system, and the types of issues the data will be used to address. In general, the purposes that states have articulated to date reflect the need for comprehensive, multi-payer data that allows state and other stakeholders to understand the cost, quality, and utilization of health care for their citizens. Increasingly, states are looking to APCDs to meet growing population health and health reform needs.

Many states specify the vision for the system within their enabling legislation. Table 1 provides example language from selected states' legislations, which demonstrates how broad or specific the purpose statement can be.

TABLE 1: EXAMPLE APCD STATEMENTS OF PURPOSE

STATE	PURPOSE
Maine[1]	Maine: Title 22, Subtitle 6, Chapter 1683 …create and maintain a useful, objective, reliable and comprehensive health information database that is used to improve the health of Maine citizens and to issue reports
Utah[2]	Utah: 26-33a-104 …a statewide effort to collect, analyze, and, distribute health care data to facilitate the promotion and accessibility of quality and cost-effective health care and also to facilitate interaction among those with concern for health care issues
Vermont[3]	Vermont: Title 18, Section 9410(a)(1) (A) determining the capacity and distribution of existing resources; (B) identifying health care needs and informing health care policy; (C) evaluating the effectiveness of intervention programs on improving patient outcomes; (D) comparing costs between various treatment settings and approaches; (E) providing information to consumers and purchasers of health care; and (F) improving the quality and affordability of patient health care and health care coverage.
Oregon[4]	Oregon: 442.466 442.466 Health care 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 health care data for the following purposes: (a) Determining the maximum capacity and distribution of existing resources allocated to health care. (b) Identifying the demands for health care. (c) Allowing health care 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 health care. (g) Improving the quality and affordability of health care and health care 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.
Colorado[5]	Colorado: 1.200.4 APCD Reports 1.200.4.A. The administrator shall, at a minimum, issue reports from the APCD data at an aggregate level to describe patterns of incidence and variation of targeted medical conditions, state and regional cost patterns and utilization of services. 1.200.4.B. The APCD reports shall be available to the public on consumer facing websites and shall provide aggregate and summary reports to achieve the purposes of the APCD. Any such reports shall protect patient identity in accordance with HIPAA's standard for the de-identification of protected health information.

TABLE 1: EXAMPLE APCD STATEMENTS OF PURPOSE CONT'D

STATE	PURPOSE
Minnesota[6]	Minnesota Statutes 62.04, Subd. 11. Restricted uses of the all-payer claims data. The commissioner (of Health) or the commissioner's designee shall only use the data submitted under subdivisions 4 and 5 for the following purposes: (1) to evaluate the performance of the health care home program as authorized under sections 256B.0751, subdivision 6, and 256B.0752, subdivision 2; (2) to study, in collaboration with the reducing avoidable readmissions effectively (RARE) campaign, hospital readmission trends and rates; (3) to analyze variations in health care costs, quality, utilization, and illness burden based on geographical areas or populations; and (4) to evaluate the state innovation model (SIM) testing grant received by the Departments of Health and Human Services, including the analysis of health care cost, quality, and utilization baseline and trend information for targeted populations and communities. (b) The commissioner may publish the results of the authorized uses identified in paragraph (a) so long as the data released publicly do not contain information or descriptions in which the identity of individual hospitals, clinics, or other providers may be discerned. (c) Nothing in this subdivision shall be construed to prohibit the commissioner from using the data collected under subdivision 4 to complete the state-based risk adjustment system assessment due to the legislature on October 1, 2015.

Stakeholder Engagement

The APCD development effort typically emerges to support a state initiative, from the interest of a legislative supporter, or as the result of a health commission that identifies the need for transparency. Stakeholders typically desire comparative information to serve multiple needs, including health care reform and informed state policy. An initial organization often serves as a champion for the efforts to develop an APCD, and it also identifies and convenes key stakeholders in the state to move the APCD development efforts forward. Many different organizations have historically played the role of the champion, including state insurance departments, state health departments, Governor's offices, legislators, and non-profit health care cost and quality organizations. In many states, multiple groups have worked together as champions to move the development effort forward.

While the convening entity for state APCD program development can vary from state-to-state, the critical role of stakeholders is common across all states. States have found that the broader the base of stakeholder support, the greater the chances are for success. A collaborative, transparent, and inclusive process will facilitate active stakeholder input about the scope, challenges, and approaches for a state APCD. The purpose of the APCD and the constitution of the stakeholder group are inter-related issues, and the stakeholder group should include those organizations that the state believes will be key users of the data. Table 2 summarizes the common key stakeholders and the role or perspective each group brings.

One of the key, initial functions of the stakeholder group is to develop what are called "use cases." Use cases define what questions the APCD will answer for which stakeholders. Having input about the intended use cases of the data is key to ensuring that the data system is later developed in a way that ensures that the use cases can be supported. The APCD Showcase provides much more information about various use cases for APCDs.

While key considerations for the stakeholder groups are described below, later sections of this manual will describe specific issues about APCD development in more detail.

Policy Makers

Policy makers are generally interested in an APCD as a tool that can provide data to support informed health policy and health care reform efforts. Policy makers can serve as champions of APCD development, with the instrumental role of sponsoring the enabling legislation to develop the APCD in a state. However, not all policy makers are likely to be aligned with the APCD efforts, and states can expect to need to address concerns of those that are not supportive of the APCD effort. Policy makers in a state often participate in stakeholder meetings to understand (1) the use cases of APCDs; (2) which state agencies need to be included for APCD operations; (3) the anticipated costs of the system; and (4) the concerns of other stakeholders. This is critical for ensuring that the legislation, rules, and policies reflect the scope and intent of the system (see Section 2: Governance).

Policy makers' initial key concerns about APCD development are often related to the costs and infrastructure requirements associated with developing and maintaining the APCD system. Early on, states benefit from identifying a diversified funding structure in the APCD development process (see Section 3: Funding). As the APCD implementation progresses, policy makers may expect an early demonstration of the APCD's value or return on the initial investment. Staging data reports and release (see Section 5: Analytics and Applications Development) will serve to build value in the data. Maintaining frequent communication with, and education of, policy makers about the complexities of APCD development will help manage unrealistic expectations (see Section 6: Feedback Loops and Continuous Engagement). In addition, policy makers are interested in ensuring that sufficient protections are in place to safeguard data stored within the system and in data products that are released, and to protect privacy. Addressing these concerns is handled by reviewing best practices in data storage and release (see Section 4: Technical Build) and specifying data security and protection parameters in the system requirement specifications.

Examples of uses of APCD data that can be relevant for policy makers include Colorado's Center for Improving Value in Health Care (CIVHC) reports highlighting variation in regional health care utilization and expenditure on a population basis by county and other geographic groupings. Among the reports in the Massachusetts Health System Performance Reports is a spending report that provides policy makers local expenditure growth trends, with exploration of growth by service category, and assessments of out-of-pocket spending.

Payers

Payers (also referred to as "carriers", "insurers" or "plans" in different states) are the primary submitters of the data to an APCD. Because of this, there is both a technical and financial burden to the payers associated with data submission. Involving payers early in stakeholder discussions allows a state to discuss a number of key issues related to data submission, including the data submission process, data quality expectations, release schedules, and intended use cases. In addition, payers
can be interested as data and analysis users themselves, often for comparison to other payers. Strong payer relationships are key for a successful APCD.

A key concern for the payer community is the set of implications related to data submissions. An important reason to include payers in the early stakeholder discussions--and throughout the APCD development and continual operations--is to allow for payer input that ensures that rules and data submission guides reflect what is feasible for data collection. That is, states may be interested in measuring certain things about the health care landscape using claims data, but the payers' data systems may not reliably include information to address the issue of interest. For example, states are often interested in analyses using race and ethnicity, and the payer community typically cautions states that any capture of that information may not be reliable, if it is captured at all. States may also reduce the impact to payers by adopting existing standards for data collection, described in more detail in Section 4: Technical Build. This allows payers to reuse technical code and processes to support multiple state APCD efforts.

Addressing these issues is typically handled by the state's establishment and documentation of transparent protocols for data submission, aggregation, and release. Payers will also require time to provide feedback and input into data collection rules, data submission guides, and intended use of data--all issues addressed by Advisory Groups (see Section 2: Governance).

Payers have routinely expressed concern about the analysis of data that would allow the disclosure of negotiated rates and what implications that might have from an antitrust perspective. Individual states have interpreted the need to restrict the display of analysis by payer and by provider differently. In Colorado, CIVHC has reviewed the issue and shared the guidance it is using for itself, based on a legal review.

Examples of uses of APCD data that can be relevant for payers include the work that Massachusetts has done across state agencies and with the payer community to find ways to use the APCD data being submitted to the Center for Healthcare Information and Analysis (CHIA) to meet the needs for Insurance Department reporting requirements. In New Hampshire, payers are part of the Accountable Care Project and have provided input, and have access to, a suite of reports that demonstrate trends in health care cost and utilization in different ways, including by payer.

Health Care Providers

Health care providers, typically through hospital associations and provider associations, are often interested in knowing how APCD data will be used, especially if there are intentions to analyze and report APCD at the health care system (or provider) levels. Providers have historically felt that claims data (and billing practices) are not accurate enough to support reporting at the individual provider level. Some states have reported data at higher level of aggregation than individual providers (i.e., hospital, clinic, or laboratory) to address concerns about data quality at the individual provider level. Health care providers also have a role in ensuring that the billing data reflect individual provider activity, so that the data accurately reflect (and can be reported at) the provider level. Engaging health care providers in the use case development will often assist in improving the utility of the data.

Examples of uses of APCD data that can be relevant for health care providers include the New Hampshire Accountable Care Project, which allows health care organizations to see regional level reporting about cost, utilization, and disease characteristics, providing population health information about the geographic areas in which health care organizations provide services. CIVHC is also developing provider level reports, in addition to its release of health care facility level reporting. In Vermont, the APCD data is being used to evaluate the Blueprint for Health, the multi-payer advanced primary care medical home program.

Employers and Employer Coalitions

Employers and employer coalitions often have a keen interest in how APCD data can provide a more robust picture of the cost of health care services than employers can receive by reviewing claims reports just for their employees. In addition, employers may see APCDs as a mechanism to support price transparency efforts for cost containment. Employer use cases may also drive the development of employer-specific tools that provide benchmarks and allow for consumer-friendly price transparency.

More than half of employers in many states are self-insured, and some states struggle initially with whether or not they can collect self-insured data for their APCDs. States should clearly specify requirements of which reporting entities

(e.g., Third Party Administrators (TPA), Pharmacy Benefit Managers (PBM), etc.) in their enabling legislation and/or data collection rules. Some data submitters have challenged state laws under the premise that the federal Employee Retirement Income Security Act (ERISA) pre-empts the state requirement for TPAs to submit data. Cases have been brought before federal courts in Maine *(Patient Advocates, LLC v. Prysunka, No. 03-118-P-H, 2004 WL 114980)* and 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)*. The results have depended on different plantiffs, complaints, facts, state laws, and legal strategies. The federal district court in Maine found in favor of the state's conduct and did not impede the Maine APCD. In Vermont, Liberty Mutual, Inc., a large employer that provides a self-funded ERISA plan to its employees, instructed its third-party administrator not to provide data to the Vermont APCD. In 2012, the federal district court determined that the state law requiring reporting to the Vermont APCD did not interfere with ERISA. By a 2-1 vote, a judicial panel from the Second Circuit Court of Appeals overruled the lower court and held that state laws could not "burden" self-funded ERISA plans with compliance of reporting claims data to an APCD (the third judge agreed with the State position). In August 2014, Vermont petitioned the U.S. Supreme Court for review of the Second Circuit's decision and that petition remains pending as of February 2015. To date, the exclusion of plans due to ERISA concerns has not proven to be a challenge preventing state APCD development; notebly, in Vermont, while one data submission has been withheld, the APCD has not been otherwise disrupted.

Examples of uses of APCD data that can be relevant for employers include the regional health care cost and utilizations reports previously described, which allow employers to benchmark their own population to regional and state comparators. In addition, Maine, New Hampshire, Massachusetts, and Colorado have created tools for understanding the variation in the costs of health care services and procedures, which can promote consumer shopping. This can support the employers' efforts for cost containment for their employee populations.

State Agencies

State agencies typically provide a critical role in APCD development. Generally, state health departments and state insurance departments are the state agencies charged with APCD governance, and they are also typically key users of the APCD data (see Section 2: Governance). State agencies also maintain other public data sets that could be linked to the APCD in the future. These agencies have experience maintaining other health data collection systems, such as hospital discharge data, and have the authority (i.e., for data collection and reporting for public health surveillance activities) and infrastructure that can be leveraged for the basis of the APCD. For example, many states use the data infrastructure of the hospital discharge, Medicaid, or other data systems in building the APCD platform. Likewise, the potential to enhance and streamline regulatory reporting across various state agencies not only reduces industry reporting burden but may provide more robust regulatory information.

Given Medicaid expansion efforts and the need to manage growing state budgets, Medicaid programs are increasingly becoming important APCD stakeholders. Medicaid data are almost always included in APCDs, and Medicaid is often a user of APCD data to design and evaluate health care and payment reform initiatives. When Medicaid data are integrated with other information, such as commercial carrier claims, the Medicaid program has access to comparative benchmarks for measuring quality and improving outcomes. Several states have successfully leveraged Medicaid matching funds for APCD development and maintenance (see Section 3: Funding). State public health programs are other potential users of APCD information for surveillance of chronic disease, injury, and other population health issues.

To maximize the use of the APCD and provide for cross-agency applications, states structure governance agreements such as Memorandums of Understanding (MOU), Data Use Agreements (DUA), and other arrangements to allow collaboration across state entities. These agreements document roles, access to, and use of data. For example, the components of the MOU in New Hampshire, between the NH Department of Health and Human Services (NH DHHS) and NH Insurance Department (NHID) include[7]:

› *NH DHHS shall maintain the CHIS and bear all expenses associated with the collection of healthcare data and its maintenance in the CHIS and develop procedures for the submission and storage of data;*

- *NHID shall adopt administrative rules relative to the submission of commercial health care claims data and the HEDIS data set;*
- *NH DHHS and NHID should work collaboratively to develop policies for dissemination of data from the CHIS; and*
- *In addition to commercial claims and HEDIS data, the CHIS shall also maintain Medicaid claims data for use by the two departments.*

Examples of uses of APCD data that can be relevant for state agencies include population health reports in New Hampshire for use in community health assessment (typically a public health activity), a Medicaid Quality Indicators report in New Hampshire, and the Medicaid Costs of Care Comparisons from CIVHC. Massachusetts publishes a Cost Trend Report that is relevant to a number of state agencies as a tool to track health reform efforts. Multiple states are developing or expanding existing APCDs to support Rate Review efforts associated with Center for Consumer Information & Insurance Oversight (CCIIO), often in conjunction with State Departments of Insurance.

Consumers

APCD data, if analyzed and published for consumer purposes, can inform a consumer's understanding of health care spending and assist in making informed choices about health care services. Comparative provider cost, price, and quality information for common medical procedures can be especially valuable to people with high deductible health plans and medical savings accounts, who would like to make decisions about the location of care, taking cost into consideration. As an example, multiple states have developed, or plan to develop, consumer portals for price transparency. Consumer stakeholders will need to be assured that privacy and security of confidential data is protected through robust data safeguards for collection, storage, and release of data (see Section 4: Technical Build).

Examples of uses of APCD data relevant to consumers include price transparency tools in Massachusetts, Maine, New Hampshire, and Colorado. These tools provide information about the costs of health care services and procedures, which are designed to assist consumer "shop" for medical services, often focused on high-deductible benefit plans.

Researchers

Researchers, particularly in health care services research, utilize APCD data for multiple purposes. The research community in a state will be concerned with limits or restrictions on data access, so their participation in the stakeholder conversations are beneficial to determining how data release policies will be structured. Additionally, early stakeholder engagement of the local research community can provide input into how data will be used.

As states have developed research release protocols, many states have noted that data requests from the academic community have increased. As an example, The Dartmouth Institute (TDI) published a "Dartmouth Atlas of Children's Health Care of Northern New England" (Goodman, et. al, December 2013), including analysis from multiple states' APCD data[8].

Health Information Exchanges (HIE) and Health Insurance Exchanges (HIX)

The collection of clinical data through an HIE may be supplemented in important ways with APCD administrative data. Combining clinical data with APCD fiscal data can enhance clinical outcomes and effectiveness research studies. Also, APCD data can be useful to states electing to operate a state-based Health Insurance Exchange (HIX) as these states can use the data for their risk adjustment models. Additionally, the collection of benefit design information through an HIX may be combined with administrative claims information to provide information on how benefit design impacts health spending trends. Despite the potential benefits, many states face technical and legal barriers to the linkage between HIEs, HIXs, and APCDs. Therefore, involving stakeholders from a state HIX and HIE in APCD conversations, ideally at the earliest stages of APCD development, can provide input into the structure of the ACPD to facilitate cross-system linkage.

The linkage of HIE and HIX to APCDs is largely aspirational, although some states are working towards making those linkages possible to take advantage of the potential synergies for the projects. At this stage, most interactions to HIE and HIX reflect the common interests in the APCDs and HIE or HIX. States (e.g., Maryland and Rhode Island) are working with their HIX, for example, to develop common provider and/or patient directories.

TABLE 2: COMMON APCD STAKEHOLDER MEMBERS

STAKEHOLDER	INTEREST IN APCD	ROLE	PRIMARY CONCERN(S) WITH APCD DEVELOPMENT	APPROACH TO ADDRESS CONCERN
Policy Makers	APCDs as a mechanism to provide data to support informed health policy and support health care reform efforts Can serve as a champion for APCD development	Support and sponsor legislation Ensure that legislation is complete and reflects the full scope of issues that need to be addressed	Cost and infrastructure requirements of APCD development Ensuring that sufficient protections are in place to safeguard data	Robust stakeholder engagement Identify diversified funding structure Build off existing systems and legislation for data collection, data security, and data release to minimize costs and leverage data management infrastructure
Payers	Key submitters of the data Have a technical and financial burden associated with data submission Interested in the results of data analysis and who will have access to the data	Provide input to ensure that rules and data submission guides reflect what is feasible for reasonable data collection Input into data uses Provide insight about data sources, including data limitations	Burden of data submissions Disclosure of negotiated rates	Include payers at the beginning and throughout the APCD cycle Include time for payers to provide feedback and input into data collection rules, data submission guides, and intended data uses Ensure compliance with HIPAA, HITECH, and address anti-trust concerns Establish and document transparent protocols for data file and data analysis release Use existing standards for data collection to minimize burden for submission
Health Care Providers	Interested in knowing how APCD data will be used	Provide input into how data will be used In health services research settings, will be users of the data	Believe that claims data (and billing practices) are not accurate enough to support reporting at the individual provider level	Include time in stakeholder sessions to understand concerns of providers, particularly in data use Can use higher level of aggregation than individual providers to address concerns about data quality at the individual provider level, as an initial step

TABLE 2: COMMON APCD STAKEHOLDER MEMBERS CONT'D

STAKEHOLDER	INTEREST IN APCD	ROLE	PRIMARY CONCERN(S) WITH APCD DEVELOPMENT	APPROACH TO ADDRESS CONCERN
Employers and Employer Coalitions	Provide a more robust picture of the cost of health care services than employers can receive by reviewing claims reports just for their employees May see APCDs as a mechanism to support price transparency efforts for cost containment Self-insured employers may be interested in requirement by "states for TPAs to submit data	Provide input into data release policies and analysis plans Provide feedback on scope of legislation about TPA submissions for self-insured plans	Ensure that there are data analyses and/or tools released that provides benchmarks and allow for consumer-friendly price transparency Uncertainty of requirements to have TPA submit data to APCD for self-insured (ERISA) plans	Include employer representation in stakeholder groups to ensure needs are met Specify requirements of reporting entities (TPA and self-insured) in legislation Employers recognizing statewide APCD benefits could respond to TPA resistance to data submission by requiring APCD reporting
State Agencies	APCD governance and use of the APCD data Previous experience maintaining other health data collection systems, such as hospital discharge data, and the authority and infrastructure that can be the basis for the APCD Medicaid agencies have an interest in statewide APCD data for analytics, benchmarks, policy and planning	Establish appropriate governance structure for the APCD Determine which agencies should fund, have authority for oversight, and use data State agencies, including Medicaid, may sponsor applications for Medicare data	Funding mechanisms Structure of governance agreements to maximize the use of the APCD and provide for adminis-trative uses across state agencies Oversight of data release policies	Establish Memorandums of Understanding, Data Use Agreements, and arrangements to define roles in the system, access to system, and use of data

TABLE 2: COMMON APCD STAKEHOLDER MEMBERS CONT'D

STAKEHOLDER	INTEREST IN APCD	ROLE	PRIMARY CONCERN(S) WITH APCD DEVELOPMENT	APPROACH TO ADDRESS CONCERN
Consumers	Can inform consumer understanding of health care spending and choices about access and quality of health care services	Provide input into how data will be used Represent consumers' interests in protecting data Participate in focus groups	Ensure that tools and analysis are useful and understandable by consumers Privacy concerns	Include consumer representation in stakeholders groups to ensure that the data analysis and tools meet consumer needs Robust data safeguards for collection, storage, and release of data
Researchers	Interested in access to and uses of APCD data	Provide input into how data will be used and how data release policies and fee schedules should be structured	Limits or restrictions on data access and use Data linkage Cost of data	Include researchers in stakeholder groups, with particular focus on establishing data release policies
Health Information Exchanges (HIE)	Collection of clinical data through an HIE may be supplemented with the financial information from an APCD	Provide input into the structure of the ACPD to facilitate cross-system linkage and shared solutions	Technical and legal barriers for the linking of the data, and for common issues across the HIE and APCD	Include HIE leadership in APCD stakeholder groups to fully explore possible collaboration and partnership
Health Insurance Exchanges (HIX)	Collection of benefit design information through an HIX may be supplemented with the financial information from an APCD Use of APCD data for rate review programs Development of consumer decision support tools to facilitate plan selection based on claims history	Providing input into the structure of the ACPD to facilitate cross-system linkage and shared solutions	Technical and legal barriers for the linking of the data, and for common issues across the HIX and APCD	Include HIX leadership in APCD stakeholder groups to fully explore possible collaboration and partnership

Once the stakeholders for a state are identified, states should develop an outreach plan to formalize stakeholder connections. States often do this via a series of meetings with the stakeholder groups, often around a common table, to discuss issues in an open and transparent way. The level of involvement for each stakeholder group will vary from state to state. Some states might find that their employer community, for example, wants to be very engaged in the development discussions, while others will find that there is a lack of interest among that group. As time passes, the stakeholder group may evolve into a more structured group such as a formal steering or advisory committee. Section 2: Governance describes the establishment and role of the formal steering committee (or advisory group) in more detail. Finally, while engagement is considered a key first step in APCD development, the stakeholder group can be an ongoing body to provide input and oversight, as described in Section 6: Demonstrating the Feedback Loop and Continual Processes.

Conclusion

Engagement for APCD development includes a range of stakeholders representing different perspectives and areas of interest. Successful APCD development in an individual state will require comprehensive engagement of these varied partners, resulting in a share vision. By defining the vision for the system, the key contributors to it (e.g., resources, data, and infrastructure), and the intended use cases for the data, states can develop the list of key stakeholders to involve in the engagement process. While the overall mix and level of engagement for various parties may vary state-to-state, one very consistent experience across states is that good payer relationships are key to a successful APCD.

ENGAGEMENT ASSESSMENT CHECKLIST

STEP	WORKSHEET/TOOL	COMPLETE
List the anticipated use cases for the data	Engagement Assessment - Use Cases Worksheet	
List the stakeholders and their positions	Engagement Assessment - Stakeholders Worksheet	
List other data efforts in the state that may be connected to the APCD	Engagement Assessment - Data Efforts Worksheet	
List the carriers and their market share, including public payers and plans for data inclusion	Engagement Assessment - Payer and Market Assessment Worksheet	
List the approaches to handling the legal barriers that may be relevant in that state	Engagement Assessment - Legal Barriers Worksheet	

SECTION 2:

Governance

Governance covers a broad array of aspects of the APCD, including authorizing legislation, data collection and release rules, oversight entity for the APCD (i.e., governmental or designated non-profit), and the composition of a board for governance. These components form the foundational structure of the APCD and have bearing on all aspects of the technical build and use of the APCD. Governance considerations, like all aspects of APCD development, need to be reviewed periodically to ensure that the APCD adapts to meet evolving needs.

Learning Objectives:

- How is governance defined?
- Why are governance issues important for APCD development?
- What is the purpose of governance?
- What issues and practices should be considered to ensure competent governance?

APCD Legislation

The majority of APCDs established in the last 10 years were created via legislative statute as mandatory reporting initiatives, which require payers to comply with data collection and reporting. Additionally, several states have created voluntary reporting initiatives, which rely on non-mandatory submission of data by carriers to the state.

For a state-mandated APCD, broad governance parameters are typically defined by the legislation that authorizes the APCD. At the most basic level, legislation to create an APCD needs to include two things:

- *Specific legal authority to define data submitters, including the specification of PBMs and TPAs as data submitters*
- *The authority to enforce its provisions, such as penalties for data submitters that do not report, or for misuse of the data*

More specific elements of the system and developmental procedures may be included in the legislation; however, the details of how the system will be operationalized are typically articulated via rule-making procedures and data submission specifications. This allows for the ability to make changes to future APCD requirements without requiring legislative action.

Some states have been able to modify existing legislation to facilitate the development of the APCD. For example, New York modified the existing authority for collection of hospital discharge data. Similarly, Connecticut has created legislation that integrates their claims data collection with their HIX.

In general, APCD legislation addresses six (6) critical elements. Each of these is described in more detail, with example state language of the sections in Table 3:

- *Purpose*
- *Governing Body and Oversight*
- *Scope*
- *Privacy and Confidentiality*
- *Funding*
- *Reporting Requirements*

Purpose

Though the inherent purpose of legislation is to authorize the creation of an APCD system, the purpose section of APCD legislation typically outlines the goals, expectations, and limits of the APCD. APCDs serve different purposes for each state, and it is crucial that these purposes be clarified within the legislation. APCDs can have extremely narrow focuses and uses, such as in Minnesota's initial APCD legislation, (which limited to use to specific reports and allowed access to the health department only), or be quite broad, such as in Maine (used to "improve the health of Maine citizens"). The purpose will match the state intent for use of the system, and states with broad purpose statements have found that they have had the flexibility to use the APCD data to address issues that have evolved over time (e.g., the need to evaluate medical home initiatives associated with the Affordable Care Act implementation). Clarity around purpose (e.g., utilization, cost, quality, health reform support, population health) will allow stakeholders to understand the purpose of the APCD in the beginning and make

the role of sub-groups, such as data release committees, easier once the APCD is implemented. Declaring which stakeholders (e.g., consumers, employers, providers, and government agencies) will be able to have access to the data will reduce problems after data collection is complete, and data are ready for public release.

Governing Body and Oversight

The governing entity responsible for APCD oversight varies by state and is typically identified in the legislation. One of the primary oversight functions of the governing entity is to ensure that the infrastructure to collect, maintain, and disseminate the data are in place. Additionally, the governing entity is charged with ensuring collection of the data, including the administration of any penalties for non-compliance of data submissions. The governing entity is also typically responsible for the financial and staffing resources required to manage the APCD. Existing oversight models include:

- *Department of Health (Utah, Minnesota)*
- *Independent state agency (Maine, Vermont)*
- *Health and insurance departments with overlapping responsibilities (New Hampshire)*
- *Independent, non-partisan, non-profit organization (Colorado, Virginia)*

Many states create steering committees that are responsible for the development of the APCD as well as its ongoing maintenance (see Table 3 for examples of the constitution of oversight boards in Colorado and Maine). The committees are often extensions of the stakeholder groups created in the planning phase of the APCD. In a similar vein, once data are available for release, states create data release committees to review the requests and ensure they are meeting the state's legislative and rules requirements. Two examples of such groups are the Massachusetts' APCD User Workgroup and Colorado's Data Release Review Committee. The Vermont Green Mountain Care Board implemented a Data Governance Council composed of voting members and non-voting participants to address data quality and utility, risk, financial sustainability, and data release. As more states develop their linkage policies (see Privacy and Confidentiality section below), these data release committees will take on larger roles.

While no one oversight model is generally better than another, the oversight

model selected should be the one that best leverages infrastructure capacity, resources, and funding opportunities for an individual state.

Scope

Items typically discussed in the legislation that address and define the scope of an APCD are:

- *File types to be collected (medical, pharmacy, dental, eligibility, provider)*
- *Lines of business included/excluded (fully insured plans, self-funded coverage, accident, disability)*
- *Entities reporting (carriers, TPAs, PBMs)*
- *Thresholds for data submission by payers, typically defined by the number of people covered by the*
- *Schedule for data submissions*
- *Language around authority to enforce provisions, such as penalties for payers that do not report or for misuse of the data*

As discussed in Section 4: Technical Build, states will vary in the scope of which reporting entities are included in the APCD, based on a number of factors: need for/interest in certain types of data (e.g., does the state intend to include dental data); the state interest in collecting data from all payers, or only those over certain thresholds; the state's assessment of the authority to mandate collection for self-insured plans; and state's assessment of its resources to accept files at certain frequencies.

Privacy and Confidentiality

A core decision for any APCD is how to protect patient identifying information. Protections are essential for building public trust in the system while creating value through appropriate use and access of the information. Determining what data will be collected, as well as what information will be released and to whom can be the most sensitive aspect of APCD implementation. During these deliberations, it is important to distinguish between the collection policies and release policies. While sensitive and confidential information is typically collected, this information is secured and not released without safeguards (e.g., de-identification, DUAs, and state agency review of reports before release).

Data Collection

States vary in their approach to collecting patient data fields. About half of the states currently only allow de-identified patient information to be collected, typically encrypting sensitive data fields. Ideally, the encryption methodology is consistent across each data submitter, such that individuals can be statistically tracked across payers. There is a recent trend in states to collect direct and indirect patient identifiers (names, dates of birth, addresses) which are typically encrypted after collection during the data aggregation process. The ability to collect patient identifiers requires discussion and debate as to how the information will be used, whom will have access, and under what circumstances. The collection of patient fields will enable future data linkages to public health, clinical, and other datasets. It should also be noted that data linkage is a difficult and resource-intensive undertaking, even with robust patient identifiers. Collection and linkage policies are nascent in their development, and will require diligence and cooperation amongst stakeholders. Despite the challenges, it should be recognized that APCD systems without these fields will not be able to conduct cross-system linkages and analytics in the future. One state, Rhode Island, has legislation[9] allowing for a patient to opt-out of the dataset via the carrier; however, operationalizing policies such as this are challenging.

Data Release

There is significant variation in data release policies and practices across states, reflecting differing viewpoints about the balance between making the data available for use and controlling release to address concerns about patient privacy. Regulations that specify data access and release policies vary according to state legal and political environments (e.g., Minnesota does not release data to external organizations because of privacy concerns; Maine restricts the identification of provider discount arrangements). In some states, de-identified and research files are made available for qualified users and uses. Other states limit data access to state government only. A few states prohibit the provision of individual data to multi-state or national databases. Providers and payers have additional concerns about data release, particularly around disclosure of payment information vis-a-vis potential antitrust concerns. Some states are assessing release options that range from the release of data to public users to restricting access via secure portals. Each approach has benefits and trade-offs for stakeholders to consider.

Many states refer to HIPAA for guidance in defining release policies. The Privacy Rule specifically does not preempt contrary state public health laws that provide for the reporting of disease or injury, child abuse, birth or death, or for the conduct of public health surveillance, investigation, or intervention [45 CFR § 160.202][10]. Preemption of a contrary state law will not occur if the US Department of Health and Human Services (DHHS) determines that the state law 1) is necessary to prevent fraud and abuse related to the provision of or payment for health care; 2) is necessary to ensure appropriate state regulation of insurance and health plans to the extent expressly authorized by statute or regulation; 3) is necessary for state reporting on health care delivery or costs; or 4) is necessary to serve a compelling public health, safety, or welfare need. States without a state mandate that collect APCD data voluntarily from covered entities (health plans) may collect data from payers under the Treatment, Payment, Operations provisions of HIPAA. The use and release of the data should be governed through an agreement that governs the disclosure and defines the protections.

Of particular note, states often have specific data release provisions for claims related to substance abuse treatment. These policies typically restrict any release of claims related to substance abuse treatment, in response to the Act to Remedy Alcohol and Drug Abuse (Pub. L. 98-24), codified under 42 U.S.C. § 290. Under the law, there are specific provisions regarding the confidentiality of patient records and claims. Pursuant to the Act, US DHHS interpreted the statute and outlined provisions for the permitted disclosure of patient records under 42 CFR part 2. The Substance Abuse and Mental Health Services Administration (SAMHSA) has provided a number of guidance documents regarding these provisions[11]. In general, states have been cautious in their implementation of this guidance and restrict the release of substance abuse claims.

For all of these discussions, it is important to recognize that many agencies maintaining APCDs have decades of experience collecting and disseminating hospital data without privacy breaches and use similar statistical and management controls for their APCD practices.

Funding

APCDs carry a cost to a state for development and ongoing maintenance. To ensure adequate funding is available, states typically identify funding sources within their legislative framework. Each state has a different approach to

funding, and they often are required to use multiple sources (e.g., general funds, Medicaid match, other) for both short and long-term program sustainability (Section 3: Funding addresses this in more detail). While penalties for non-compliance of data submitters is often addressed in legislation, states do not consider penalties as a part of the funding mechanism. Such penalties are designed to ensure that all submitters are sending in their data regularly to promote the integrity of the overall database.

Progress Reporting Requirements

As states develop their accountability structures, one option is to define progress reporting requirements. This may include an annual report to the Governor's office, the Legislature, or a legislative committee. They may also be milestone-based (rather than at a specified time interval), such as when funds have been raised or systems implemented.

TABLE 3: EXAMPLE TEXT FOR APCD LEGISLATION SECTIONS

LEGISLATION SECTION	STATE	EXAMPLE LANGUAGE
Purpose	Maine[12]	Title 22, Chapter 1683 The purposes of the organization are to create and maintain a useful, objective, reliable and comprehensive health information database that is used to improve the health of Maine citizens and to issue reports, as provided in section 8712. This database must be publicly accessible while protecting patient confidentiality and respecting providers of care. The organization shall collect, process, analyze and report clinical, financial, quality and restructuring data as defined in this chapter.
	Utah[13]	26-33a-104 (1) The purpose of the committee is to direct a statewide effort to collect, analyze, and distribute health care data to facilitate the promotion and accessibility of quality and cost-effective health care and also to facilitate interaction among those with concern for health care issues. (2) The committee shall: (a) develop and adopt by rule, following public hearing and comment, a health data plan that shall among its elements: (i) identify the key health care issues, questions, and problems amenable to resolution or improvement through better data, more extensive or careful analysis, or improved dissemination of health data; (ii) document existing health data activities in the state to collect, organize, or make available types of data pertinent to the needs identified in Subsection (2)(a)(i); (iii) describe and prioritize the actions suitable for the committee to take in response to the needs identified in Subsection (2)(a)(i) in order to obtain or to facilitate the obtaining of needed data, and to encourage improvements in existing data collection, interpretation, and reporting activities, and indicate how those actions relate to the activities identified under Subsection (2)(a)(ii)…

TABLE 3: EXAMPLE TEXT FOR APCD LEGISLATION SECTIONS CONT'D

LEGISLATION SECTION	STATE	EXAMPLE LANGUAGE
Purpose	New Hampshire[14]	420-G:11-a The department and the department of health and human services shall enter into a memorandum of understanding for collaboration in the development of a comprehensive health care information system…To the extent allowed by HIPAA, the data shall be available as a resource for insurers, employers, providers, purchasers of health care, and state agencies to continuously review health care utilization, expenditures, and performance in New Hampshire and to enhance the ability of New Hampshire consumers and employers to make informed and cost-effective health care choices.
Oversight	Maine[15]	Title 22, Chapter 8703 2. Board of directors. The organization operates under the supervision of a board of directors, which consists of 20 voting members and one nonvoting member. A. The Governor shall appoint 18 board members in accordance with the following requirements. Appointments by the Governor are not subject to review or confirmation. (1) Four members must represent consumers. For the purposes of this section, "consumer" means a person who is not affiliated with or employed by a 3rd-party payor, a provider or an association representing those providers or those 3rd-party payors. (2) Three members must represent employers. One member must be chosen from a list provided by a health management coalition in this State. One member must be chosen from a list provided by a statewide chamber of commerce. (3) Two members must represent 3rd-party payors chosen from a list provided by a statewide organization representing 3rd-party payors. (4) Nine members must represent providers. Two provider members must represent hospitals chosen from a list provided by the Maine Hospital Association. Two provider members must be physicians or representatives of physicians, one chosen from a list provided by the Maine Medical Association and one chosen from a list provided by the Maine Osteopathic Association. One provider member must be a doctor of chiropractic chosen from a list provided by a statewide chiropractic association. One provider member must be a representative, chosen from a list provided by the Maine Primary Care Association, of a federally qualified health center. One provider member must be a pharmacist chosen from a list provided by the Maine Pharmacy Association. One provider member must be a mental health provider chosen from a list provided by the Maine Association of Mental Health Services. One provider member must represent a home health care company.
	Colorado[16]	HB 10-1330 25.5-1-204. Advisory committee to establish an all-payer health claims database…the executive director shall appoint an advisory committee to make recommendations regarding the creation of the framework and implementation plan for a Colorado all-payer claims database …the executive director shall appoint an administrator of the database. (b) the executive director shall appoint the members of the Advisory committee, consisting of the following members: (i) a member of academia with experience in health care data and cost efficiency research; (ii) a representative of a statewide association of hospitals; (iii) a representative of an integrated multi-specialty organization…

TABLE 3: EXAMPLE TEXT FOR APCD LEGISLATION SECTIONS CONT'D

LEGISLATION SECTION	STATE	EXAMPLE LANGUAGE
Scope	Maryland[17]	Ann Title 10, subtitle 25 10.25.06.01. 01 Scope. A. This chapter applies to payers whose total premiums collected in the State for health benefit plans exceed $1,000,000. With the exception of Medicare supplemental plans and certain dental and vision information, the applicability of this chapter to an individual payer is based on the information reported by the payer to the Maryland Health Care Commission (MHCC) on the MHCC Fiscal Year User Fee Assessment Surveys and required under Health-General Article, §19-111,
Privacy and Confidentiality	Tennessee[18]	HB2289 (1) As required by HIPAA, the all payer claims database shall not publicly disclose any individually identifiable health information as defined in 45 C.F.R. § 160.103. Use of the all payer claims database shall be subject to restrictions required by HIPAA and other applicable privacy laws and policies. The all payer claims database shall be accessed only by staff or a designated entity authorized in writing by the commissioner of finance and administration to perform the analyses contemplated by this section. The commissioner shall collaborate with the Tennessee health information committee in developing procedures and safeguards to protect the integrity and confidentiality of any data contained in the all payer claims database.
	Vermont[19]	Title 18, Chapter 221, section 9410 (h)(3)(D) Not withstanding HIPAA or any other provision of law, the comprehensive health care information system shall not publicly disclose any data that contains personal identifiers. Records or information protected by the provisions of the physician-patient privilege under 12 V.S.A. § 1612(a), or otherwise required by law to be held confidential, shall be filed in a manner that does not disclose the identity of the protected person.
Funding	Kansas[20]	Chapter 65, article 68 Health care database fee fund; fees credited; authorized uses; interest earnings credited; administration. (a) There is hereby established in the state treasury the health care database fee fund. The Kansas health policy authority shall remit to the state treasurer, in accordance with the provisions of K.S.A. 75-4215, and amendments thereto, all moneys collected or received by the authority from the following sources: (1) Fees collected under K.S.A 65-6804, and amendments thereto; (2) moneys received by the authority in the form of gifts, donations or grants; (3) interest attributable to investment of moneys in the fund; and (4) any other moneys provided by law…
	Maine[21]	Title 22, Chapter 100 A payer that fails to file health care claims data and/or to meet the standards for data and the provisions for compliance as set forth in 90-590 C.M.R Chapter 243 is considered in civil violation under 22 M.R.S.A. §8705-A for which fines may be adjudged as follows: 1. $100 per day for the first week of non-compliance; 2. $250 per day for the second week of non-compliance; 3. $500 per day for the third week of non-compliance; and 4. $1,000 per day for the fourth week of non-compliance and each week thereafter, not to exceed a maximum of $25,000 per any one occurrence.

TABLE 3: EXAMPLE TEXT FOR APCD LEGISLATION SECTIONS CONT'D

LEGISLATION SECTION	STATE	EXAMPLE LANGUAGE
Reporting Requirements	Colorado[22]	HB 10-1330, Chapter 229 (h) Report to the governor and the general assembly on or before March 1of each year on the status of implementing the database and any recommendations for statutory or regulatory changes, with input from the advisory committee or its successor governance entity, that would advance the purposes of this section
	Minnesota[23]	62U.04 Payment Reform; Health Care Costs; Quality Outcomes. Subd. 4.Encounter data. (a) Beginning July 1, 2009, and every six months thereafter, all health plan companies and third-party administrators shall submit encounter data to a private entity designated by the commissioner of health. The data shall be submitted in a form and manner specified by the commissioner subject to the following requirements…
	New York[24]	Public Health 2816 9. The commissioner shall publish an annual report relating to health care utilization, cost, quality, and safety, including data on health disparities.

Rules and Regulations

In addition to the creation of enabling legislation, rules or regulations are another key component to guide the APCD. In general, states need to determine what level of detail should be included in legislation versus rules or regulations. Rules and regulations are used rather than legislation, because the process to make changes to APCD protocols in rules or regulations is more efficient than changing legislation. These decisions are state-specific, reflecting the individual legislative process.

Rules or regulations typically define:

- *Data elements and definitions for collection*
- *Thresholds for required data submissions*
- *Submission format and timelines*
- *Review and validation process*
- *Penalties for noncompliance*
- *Data release and use policies*

Section 4. Technical Build provides more detail about these aspects of APCD development.

Other details that might be addressed in regulations include:

- *Interagency agreements required, particularly if the governance is housed in a non-state entity (Colorado, Virginia)*
- *Requirements for encryption to protect sensitive fields (Maryland, New Hampshire, Vermont)*
- *Schedule for mandatory data reporting, to provide assurances in rule that data will be used to meet the needs of the system (Colorado, Maryland, Minnesota, Tennessee, Vermont, Virginia)*

Conclusion

In summary, while the parameters of governance are similar state-to-state, the specific components of governance vary to meet the needs of the individual state. The final governance parameters in legislation, rules, and policies will reflect the state's intended use of the data, political environment, oversight of the system, and assurances for privacy and data use.

GOVERNANCE ASSESSMENT CHECKLIST

STEP	WORKSHEET/TOOL	COMPLETE
Determine key characteristics of the APCD: -Voluntary or mandated reporting › Establish authority for data collection › Legislation components	Governance Assessment Checklist - Governance Considerations Worksheet	
Determine components of rules and regulation: › Guiding documents (data submission rules, data release policies) › Oversight bodies › MOUs	Governance Assessment Checklist - Rules and Regulations Worksheet	
Determine the need for boards and sub-committees and their constitution	Governance Assessment Checklist - Board Compositions Worksheet	

SECTION 3:

Funding

The ability of APCDs to serve as ongoing sources of information to monitor cost and utilization trends depends on their long-term financial sustainability. Therefore, APCD funding is a key consideration for APCD development, both at the initial development phase and as the system evolves. Understanding initial and longer term funding opportunities will inform APCD governance, technical operations, and data use. APCDs take time to initially populate and test the data, and then additional time to realize the benefits of analytics and applications. Therefore, funding should consider both start-up and longer-term needs.

Learning Objectives:

- What are the key funding issues states must address?
- What options are states employing to address funding?
- What are advantages and disadvantages of various funding models?

Funding Estimates

One of the most frequently asked questions by states beginning the APCD development process is "how much does it cost to start up and maintain an APCD system?" This is followed by "How do we fund the APCD over the long term?" Because states vary in their legal, policy, and market structures, there is no single answer. Each phase of APCD development—planning activities (stakeholder engagement, determining the governance structure), implementation activities (the actual technical build of the system), and information production (analytics and application development activities)—includes start-up and ongoing costs that require funding.

Costs for APCD planning, implementation, and maintenance vary by state. The amount needed depends on factors that impact the complexity of the system construction and maintenance, including (as described more in Section 4: Technical Build):

- *State population (e.g., number of covered lives) and insurance coverage patterns (e.g., the types of health insurance products in place for the population)*
- *State health care system market structure (e.g., the numbers and types of delivery systems and providers that are present in the state)*
- *Number of licensed payers, including TPAs and PBMs, and the number of data systems in place for those payers (e.g., many payers have multiple transaction systems housing the data)*
- *Location of the agency where the APCD is to be housed (e.g., insurance department, health department, or other type of arrangement such as a state-sponsored private entity)*
- *Planned users and uses for the APCD and associated costs of data release (e.g., if researcher access is planned, or public websites will be developed)*

Because of the differences across states, no average or single estimate will apply. Reported annual state APCD funding ranges from $350,000 to $2 million to establish the data system. These numbers are for states ranging from approximately 1.3 million to 5.5 million lives.

Funding Types

Public APCDs are typically funded by multiple sources. In general, states find that it is prudent to diversify revenue sources in order to reduce the risk of funding loss from any one source. Sources include:

- *General appropriations*
- *Fee assessments on public and private payers and facilities*
- *Grant funds (federal and/or local)*
- *Medicaid matching funds*
- *Partnerships with other initiatives (e.g., HIE and HIX)*
- *Reimbursement for data file requests*

States vary in their funding approaches, reflecting differing governance and organizational models (Table 4). A state with legislation may have general

appropriations or funding associated with the law. The interest in transparency and community improvement initiatives have led to foundation and private funding in at least one state, and this practice should be considered as states build their APCD plans. Supplementing APCD funding sources by leveraging funds from health information or insurance exchange initiatives or Medicaid are also successful strategies.

TABLE 4: FUNDING OPTIONS FOR APCDS

FUNDING OPTIONS	CONSIDERATIONS	STATE EXAMPLES
General Appropriations	The majority of APCDs have some core funding from general state appropriations. This is especially true in the start-up funding efforts, and may fluctuate based on political influence over time.	UT, NH, VT, OR, MN
Fee Assessments on Industry	Legislation will often address a fee assessment on the industry to partially fund the APCD. This becomes a sustainable source of funding, but may raise opposition from the industry community.	ME, MD, VT
Grant Funding	Federal grant funding from the State Innovation Model (SIM) or Center for Consumer Information and Insurance Oversight (CCIIO) rate review grants (both grant programs of the Centers for Medicaid and Medicare Services (CMS)) has been used to develop or add functionality to state APCDs. States have also been able to leverage funds from local foundation partners, particularly those with an interest in improving health of the population through better information about health expenditures and outcomes.	AR, ME, MA, VT, NY, UT, CO
Medicaid Match	CMS permits Medicaid match for analytic activities using the APCD data that also benefit state Medicaid programs. The Medicaid match is the federal government's share of the cost of services, and different rates of match might be appropriate for different aspects of the APCD development. For example, design/development of a data warehouse might be 90 percent federal funds and 10 percent state funds (90/10). Maintenance and operations and other functions (such as research or auditing), may have different match rates (75/25 or 50/50).	UT, NH
Partnerships with Other Initiatives	States may partner with their HIX and/or HIE programs to share data management infrastructure, align analytic activities between systems, and leverage funding across efforts.	NY, RI, CT
Reimbursement for Data File Requests	Most states will have a data request process for research studies, and charge for request fulfillment, thus creating supplemental revenues.	MA, ME, CO

As exemplified in Maine, states can develop a diverse funding structure. An assessment from Maine, in 2010, indicated that the core funding was split as follows[25]:

- *38.5% hospitals (based upon net patient service revenue)*
- *11.5% non-hospital providers (based upon fixed categorical assessments)*
- *38.5% carriers (based upon premiums written)*
- *11.5% TPA's (based upon claims paid for plan sponsors)*

Additional revenue was derived from the data fees for research files. Maine's APCD also has a set spending cap, approved annually, and funds not expended must be carried over to the next fiscal year; that year's fee assessment is reduced accordingly. This funding arrangement engages the industry in the APCD implementation and makes the state accountable to industry in how the funds are expended.

Another model for APCD governance and financing is the public-private model. The Colorado Center for Improving Value in Health Care (CIVHC) is an independent non-profit entity overseeing and managing the establishment of a statewide APCD. In 2008, Colorado's Blue Ribbon Commission on Health Care recommended that Colorado create an APCD, arguing that transparent data regarding costs and quality were necessary for Colorado to take control of spiraling health care costs. The APCD was enabled by legislation in 2010, and CIVHC was appointed administrator of the APCD. Legislation was subsequently enacted, but no general funds were appropriated for the APCD. The planning phase was supported through a grant from The Colorado Trust. Additional funding was provided from the Colorado Health Foundation and The Colorado Trust, to support initial development, implementation, and management of the APCD.

State experience in the amount of funding to support APCD from research requests has been varied. In many states data sales have not been proven to be sufficient to fund a significant portion of APCD operations, and may only be sufficient to cover the costs of maintaining a robust data request process. For many researchers, funding for data acquisition is limited. Recognizing this, CIVHC in Colorado partnered with the state Medicaid agency (Colorado Health

Care Policy and Financing) to obtain general appropriations of $500,000 per year to support approved research applications using the Colorado APCD data[26]. Overall, Colorado has been able to generate over $1 million in funding from data requests, which indicates that data sales can be important to the full sustainability plan for an APCD.

Conclusion

States are funding APCD systems through a variety of mechanisms. Costs for building and maintaining an APCD will vary across states because state markets and agency structures differ. However, all APCDs need funding sources for start-up and ongoing operations. While legislative appropriations have been the source of core funding for many existing state APCDs, there are a growing number of states using federal grants to fund their APCD programs as the need for transparency and integration is recognized. All APCD programs will benefit from diversifying revenue sources as a strategy for sustaining their systems for the long-term. Thus, APCD initiatives are actively seeking partnerships with other state agencies, such as Medicaid agencies, insurance departments, and health departments to leverage funding and align technical solutions.

FUNDING ASSESSMENT CHECKLIST

STEP	WORKSHEET/TOOL	COMPLETE
List the possible partnerships, sources of funding, and grants to address both start-up and continual funds for APCD development	Funding Assessment - Funding Sources Worksheet	
Develop plans for the distribution of research data files and structure of pricing, if applicable	Funding Assessment - Data Release Pricing Worksheet	

SECTION 4:

Technical Build

The technical build phase of the APCD development results in the operational protocols for receiving and processing the data that will be used for analytics and applications. Some states have intentionally started with a pilot or proof of concept and then moved to full-scale implementation. Other states have started with a phased approach based on legislation with full-scale implementation with commercial payers and then added Medicaid and Medicare later in development. Regardless, states will need to make decisions early on in the development of the APCD as to what data will be collected from whom and when, and whether or not the system will be built internally or outsourced to a vendor.

Learning Objectives:

- What are the components of the technical build to be considered?
- What approaches can states take to ensure a successful technical build?
- How can a state develop an RFP for data management and analytic services?

Considerations for Building an APCD

Collecting and aggregating claims data files across payers is a complex process with both technical and political challenges. States with established APCDs have learned that the reporting specifications need to align with payer system capabilities and that data quality improves over time with consistent feedback and direct consultation with each data submitter's technical staff. For example, payers may have individual provider files, home-grown code sets, and may capture the same types of data in different ways. In addition, payers may change platforms or systems in claims and eligibility systems over time or due to consolidation, which may result in data changes. Feedback with data submitters is key to understanding data changes and their impact on the APCD.

Whether an agency builds and maintains the APCD in-house or outsources data management to a vendor (or some combination of contracting and in-house systems) there are several determinants to understanding the scope of work necessary to support the APCD technical build. The complexity (and cost) of the build will be driven by many elements, including:

- *Analysis and reporting needs*
- *Volume and size of carriers*
- *Types and sizes of files*
- *Inclusion of public payers*
- *Data submission requirements*
- *Data submission schedule*

Anticipated Needs for Analysis and Reporting

Most APCDs must demonstrate a return on the initial construction investment, which is typically in the form of analytics or reporting from the APCD. One report has indicated that use of APCD data can have significant implications for health care transparency and cost savings. Analytics and reporting activities are among the most variable of all APCD system costs. Different approaches reflect the differing priorities of states, and the analytic costs depend on the nature and scope of the uses of the data. Analysis is discussed in more detail in Section 5: Analysis and Application Development.

General considerations that will shape the planning for analysis needs include:

- *What use cases are driving the data collection and dissemination strategies?*
- *What resulting information will be produced and made available?*
- *Is there an expectation for a data request and release process?*
- *Will the agency outsource the analytic functions, will analyses be conducted in-house, or will there be a combination of approaches?*
- *Who will manage the requests for data and reports to be run, and who will manage the dissemination?*
- *What resources are needed to produce data sets/reports?*

Volume and Size of Payers

While there is no uniform method to establish an APCD, there are common steps in the development process. The first step for all states is to make sure the state understands its insurance market. Most of the APCDs, to date, have defined the volume or size of the data submitters that will be required to submit claims data; this is typically the majority of licensed carriers in the state, but not all. In order to establish the right size and number of data submitters, it is important for the state to have an understanding of the carrier market and market share (discussed in Section 1: Engagement). In addition, a state needs to consider their authority to require TPAs and PBMs to submit claims data (discussed in Section 1: Engagement).

It is important to be sure that states develop an understanding of the:

- *Number of commercial payers, to understand how many feeds may be part of the system*
- *Size of the state's population, to understand how many people and claims are likely to be part of the system*
- *Mix of payers, to understand the likely relative size of the different plans compared to one another*

To help define the scope and staging of the state's APCD development, consultation should occur minimally with the following stakeholders:

- *State insurance departments, which license and regulate commercial payers, often including TPAs and PBMs*
- *Individual carriers (especially those with large commercial market share)*
- *State Medicaid program*
- *Centers for Medicare and Medicaid Services (for Medicare claims requests)*
- *State health departments or others in the state who understand the uninsured populations*

With the market information defined, the state can make decisions about determining how many and which submitters will be required to submit to the APCD. For example, a state with 90% of the insurance market split among five carriers may determine that data submission from the remaining 10% of the market (which may equate to 30 additional carriers) may not be worth the additional effort to collect and manage. The decision about the requirements

for filing and submitting claims can be written into the data submission rule. Similarly, the submission rule may allow for smaller carriers to file for an exemption from submitting data to the APCD, which may help limit the number of submitters that a state has to manage in the APCD. Alternatively, the rule may establish thresholds for the size of the data submitter's business, such that data submitters with a volume greater than a certain amount (e.g., $250,000 in premiums written, or 2,000 lives) must submit their claims.

As examples of state practices, Maine bases its collection on health plans covering more than 50 covered lives, while Utah's threshold is 2,500. In contrast to the covered lives strategy, Maryland's submission rules are based on the total dollars a plan has in annual premiums ($1 million). Alternatively, Kansas collects data from insurers based on market share (at least 1%). Minnesota uses annual patient claims amounts of $3 million for medical and $300,000 for pharmacy as reporting thresholds. In general, states have found that using covered lives thresholds is more straightforward than thresholds set on dollar values, because dollar values can be influenced by rates and premium changes.

The number of payers in each state APCD can vary. For example, the state of Vermont has seventy commercial payer feeds, and Maine has nearly ninety. Driving these totals is the fact that one commercial payer could have multiple information system platforms (typically delineated by product), each resulting in a separate set of data feeds; how many types of commercial health insurance are required to report; and how states and payers define a reporting entity in the case of subsidiaries. The APCD must interact with and test data from each separate platform and monitor compliance and data quality from all sources.

It will also be important to consider whether PBM and behavioral health carve-out vendors should be subject to data submission requirements and to make clear whether it is the primary payer that is responsible for the data submission or that the carve-out payer that will be submitting data (this can be indicated in the rule and documented by each data submitter in the registration process). If the registration process does not articulate which party is responsible for submitting claims, two data submitters may unintentionally report the same claims. Similarly, if both entities assume that the other is responsible for submitting the data, and neither entity submits, there may be gaps in the data.

Types and Size of Files

Typically, states have collected medical (professional and institutional) claims data, membership information (eligibility), and pharmacy data. Most, but not all, APCDs are requiring submission of dental claims, and the majority of APCDs require submission of a provider file. States with large populations will need sufficient computing and storage capacity to analyze and accommodate terabytes of data associated with the eligibility, medical, pharmacy, and dental claims files. For example, New Hampshire's commercial data file covers approximately 770,000 lives, and, on average, there are approximately two medical service lines, one pharmacy service line, and .25 dental service lines per active member per month. Developmental costs, maintenance, and accommodation for file consolidation will be required for states who wish to collect this information.

Recently, states have become interested in capturing non-claims based payment information in order to have a more complete picture of the cost of health care (e.g., pay-for-performance payments). However, there is no consensus on how to do that, and the collection of this information is not typical of current APCDs. The State of Maryland recently published a report discussing those issues in more detail.

Public Payers

States establishing APCDs should consider, early in the process, their intention to collect public payer data. To date, states have collected Medicaid data and/or Medicare data; other public payers (e.g., Indian Health Service and Veteran's Administration) have not been part of APCDs.

The submission of Medicaid data to the APCD should be coordinated with the state office that stewards the Medicaid data. Medicaid is typically housed in the state's Department of Health and/or Human Services. In some cases, the data steward for the Medicaid data and the office that is responsible for APCD development may need to enter into a MOU for the purpose of incorporating the Medicaid data into the APCD. States may need guidance from legal counsel

to identify the necessary agreements to allow for the data exchange.

There are multiple ways that Medicare data can be acquired for incorporation into the APCD. Some states elect to certify as Qualified Entities (QE); other states have pursued acquiring the data through the State Agency Release process. State experience has indicated that the Qualified Entity approach imposes complex requirements and is resource-intensive. States should assess the advantages and the challenges associated with the QE Certification Program before opting to go this route. Many states have taken the State Agency Release approach to access Medicare data. Through this process, states that provide data security assurances and meet the requirements stipulated in the application process can acquire data to be used for multiple purposes and under multiple funding sources, as long as the data is used at the direction of the state and the funding originates with the state.

For the technical build, the state should allow time for the cross-walking or mapping of the Medicaid and Medicare data to the commercial data. Typically, Medicaid data (which originates from a Medicaid Management Information System) is not in the same format as the commercial data (originating from various commercial platforms). Similarly, Medicare provides the claims data to states in a different format than MMIS and commercial formats. The variations in structure have not posed insurmountable obstacles for states, but the work should be factored into the technical design and system build.

Another important note about the inclusion of public payer data is that it can directly impact data release. Medicare and Medicaid data usually have unique restrictions for data release. States that are incorporating Medicaid may have to contend with additional data release policies. For example, in Colorado, requests for Medicaid-only APCD data must be reviewed and approved by the Medicaid agency (Department of Health Care Policy and Finance). Regarding Medicare data, Vermont and Massachusetts have each incorporated language in their release applications, data use agreements, and user affidavits that outline the special stipulations related to the release of Medicare data. CIVHC (in Colorado) received written approval from CMS to include Medicare as a separate category for all intended public reporting under their state agency MOU.

These considerations should be factored into the technical build of the APCD, in advance of collection of the public payer data, and certainly in advance of plans for data release.

Data Submission Manuals

Once states have conducted an inventory of the insurance market and have identified the major payers, the typical next step is the documentation phase that develops reporting rules and submission specifications. As discussed in Section 2. Governance, administrative rule making is typically the vehicle for states to clearly define the components of the APCD submissions. These components typically include:

- *The entities that are subject to the legislative authority and will be submitting data to the APCD*
- *Which files are to be submitted to the APCD*
- *Format and content of those files*
- *Schedule for submission*

Critical to the development of sound rules are discussions and technical workgroup meetings with all key stakeholders, including payers, to define the submission requirements. Data submission manuals in Massachusetts and Maine are examples of the level of detail and information that needs to be provided to guide payer data submission. Adequate time should be factored into this phase of development to allow for carrier comment on the manuals. Similarly, one major concern from payers is having adequate time to implement changes to their systems to respond to changes in the data submission requirements over time. Including payers in data submission change conversations can avoid data submission delays.

Schedule of Data Submission

Once the state has determined which entities are required to submit, the state will need to determine the frequency of data submission. This may be based on the size of the carrier, with carriers with larger volumes submitting more frequently (e.g., monthly) than the low volume carriers (e.g., quarterly). The capacity of the data processing solution may have implications on the frequency of data submissions, with the preference to process smaller amounts of data

more often, rather than trying to process large data files. This can also allow states to perform quality assurance checks on smaller amounts of data at a time.

Table 6 includes examples of key language from various states' rules and regulations to address these major aspects of the APCD technical build.

TABLE 5: EXAMPLE APCD TECHNICAL BUILD RULE LANGUAGE

TECHNICAL BUILD CONSIDERATION	STATE	EXAMPLE REGULATORY LANGUAGE
Define scope for payer reporting	Massachusetts[27]	114.5 CMR 23.00 Health Care Payer ("Payer"). A Private or Public Health Care Payer that contracts or offers to provide, deliver, arrange for, pay for, or reimburse any of the costs of health services. A Health Care Payer includes an insurance carrier, a health maintenance organization, a nonprofit hospital services corporation, a medical service corporation, Third-Party Administrators, and self-insured plans. Private Health Care Payer. A carrier authorized to transact accident and health insurance under chapter 175, a nonprofit hospital service corporation licensed under chapter 176A, a nonprofit medical service corporation licensed under chapter 176B, a dental service corporation organized under chapter 176E, an optometric service corporation organized under chapter 176F, a self-insured plan to the extent allowable under federal law governing health care provided by employers to employees, or a health maintenance organization licensed under chapter 176G. Public Health Care Payer. The Medicaid program established in chapter 118E; any carrier or other entity that contracts with the office of Medicaid or the Commonwealth Health Insurance Connector to pay for or arrange for the purchase of health care services on behalf of individuals enrolled in health coverage programs under Titles XIX or XXI, or under the Commonwealth Care Health Insurance program, including prepaid health plans subject to the provisions of section 28 of chapter 47 of the acts of 1997; the Group Insurance Commission established under chapter 32A; and any city or town with a population of more than 60,000 that has adopted chapter 32B. Payer Filing Requirements. Private Health Care Payers must file data in accordance with 114.5 CMR 21.03(3) and the Submission Guide. Public Payers and the Commonwealth Health Insurance Connector may provide or authorize the provision of claims data to the Division pursuant to an interagency service agreement.

TABLE 5: EXAMPLE APCD TECHNICAL BUILD RULE LANGUAGE CONT'D

TECHNICAL BUILD CONSIDERATION	STATE	EXAMPLE REGULATORY LANGUAGE
Define thresholds for data submission rules for the APCD	New Hampshire[28]	Ins 4004.01 (d) Third party payers that write less than $250,000 in accident and health insurance premiums in New Hampshire on an annual basis shall not be required to submit their health care claims data set, their HEDIS data, or their CAHPS survey data. (e) Third party administrators that administer health insurance plans covering fewer than 200 New Hampshire lives in total shall not be required to submit their health claims data. (f) In instances where more than one entity is involved in the administration of a policy, the health carrier shall be responsible for submitting the claims data on policies that it has written, and the third party administrator shall be responsible for submitting claims data on self-insured plans that it administers.
Define which platforms each payer must report and from which data sources (eligibility, medical, pharmacy, dental)	Vermont[29]	REGULATION H-2008-01, Section 4 Health Insurers shall regularly submit medical claims data, pharmacy claims data, member eligibility data, provider data, and other information relating to health care provided to Vermont residents and health care provided by Vermont health care providers and facilities to both Vermont residents and non-residents in specified electronic format to the Department for each health line of business (Comprehensive Major Medical, TPA/ASO, Medicare Supplemental, Medicare Part C, and Medicare Part D) per the data submission requirements contained in the appendices to this Rule.
Define file structure and file layout formats	Colorado[30]	1.200.2 Reporting Requirements Payers shall submit complete and accurate eligibility data files, medical and pharmacy claims data files and provider files to the APCD pursuant to the submission guide. The administrator may amend the submission guide and shall provide notice of the revisions to payers. Any revision to the submission guide will be effective only when incorporated into this rule and issued in compliance with the requirements of C.R.S. § 24-4-103(12.5). Reports submitted 120 days following the effective date of the revision of this rule and the submission guide shall follow the revised submission guide.

TABLE 5: EXAMPLE APCD TECHNICAL BUILD RULE LANGUAGE CONT'D

TECHNICAL BUILD CONSIDERATION	STATE	EXAMPLE REGULATORY LANGUAGE
Define the data submission schedule (monthly, quarterly, and annually)	Minnesota[31]	4653.0300 Data Submission Requirements Health plan companies, third-party administrators, and pharmacy benefit managers that meet the definition of data submitter in part 4653.0100, subpart 8, on December 31, 2008, must submit the required data on or before July 1, 2009, and at least once every six months thereafter. Health plan companies, third-party administrators, and pharmacy benefit managers that meet the definition of data submitter in part 4653.0100, subpart 8, on December 31 of any year subsequent to 2008 must submit the required data on or before July 1 of the following year and at least once every six months thereafter. Data submitters may submit the required data more frequently than every six months, but no more frequently than monthly. A. The first submission by a data submitter must be made on or before July 1 and must consist of enrollment data and data from all claims paid from January 1 of the previous year through March 31 of the current year, according to the specifications in Appendix D, to allow for testing of the compatibility of the data submitter's submissions with the data processor's system. B. Data submitters' subsequent data submissions, following the first submission, must consist of enrollment data and data from all claims paid since the last submission through at least the last day of the quarter prior to the month of submission, according to the specifications in Appendix D. For purposes of this item, a quarter ends on the last day of March, June, September, and December.

Standards, Data Elements, and Format

Defining the data elements for the APCD is a key step in the technical build. Because claims data are generated for billing purposes, the data elements are generally available across payer systems. Uniformity of data submission is important, both for reasons of comparability within and across states and to reduce the payers' burden to submit data to different states in different formats.

To address these issues, there are initiatives to standardize data reporting formats. Early efforts in standardization have resulted in industry reporting standards to align with both state reporting needs and payer reporting capabilities. As more states implement APCDs, the need for uniform reporting specifications increases in order to reduce the impact on national payers supplying the data to states. At the same time, while such standardization of data elements and format across states is beneficial for both states and payers, there needs to be some flexibility for local information needs.

APCD Core Set of Data Elements

In 2009, the APCD Council and the Agency for Healthcare Research and Quality (AHRQ) began work on the development of a common core set of data elements across the six states with active APCD systems at that time. These six states were remarkably harmonized in terms of the specific data elements being captured on each of the eligibility, medical, dental, and pharmacy files. Through a vetting process with the states, the APCD Council developed the APCD Core, a set of data elements common to most APCDs, which would provide a foundation for new states to grow their APCD.

Since that time, the APCD Council has worked with two Standards Development Organizations (SDOs), ASC X12 and the National Council for Prescription Drug Programs (NCPDP), to develop standards based on electronic transactions used for claims adjudication. In 2000, in response to the HIPAA legislation, the Secretary of Health and Human Services designated the SDOs as "organizations that maintain standards for health care transactions adopted by the Secretary, and receive and process requests for adopting a new standard or modifying an adopted standard."[32] By using the data standards from the adjudication process, states are assured of having standards that will change with the industry standards and of not using proprietary standards that may become outdated or deviate markedly from the adjudication systems used by the industry.

Using ASC X12 PACDR and NCPDP Standards

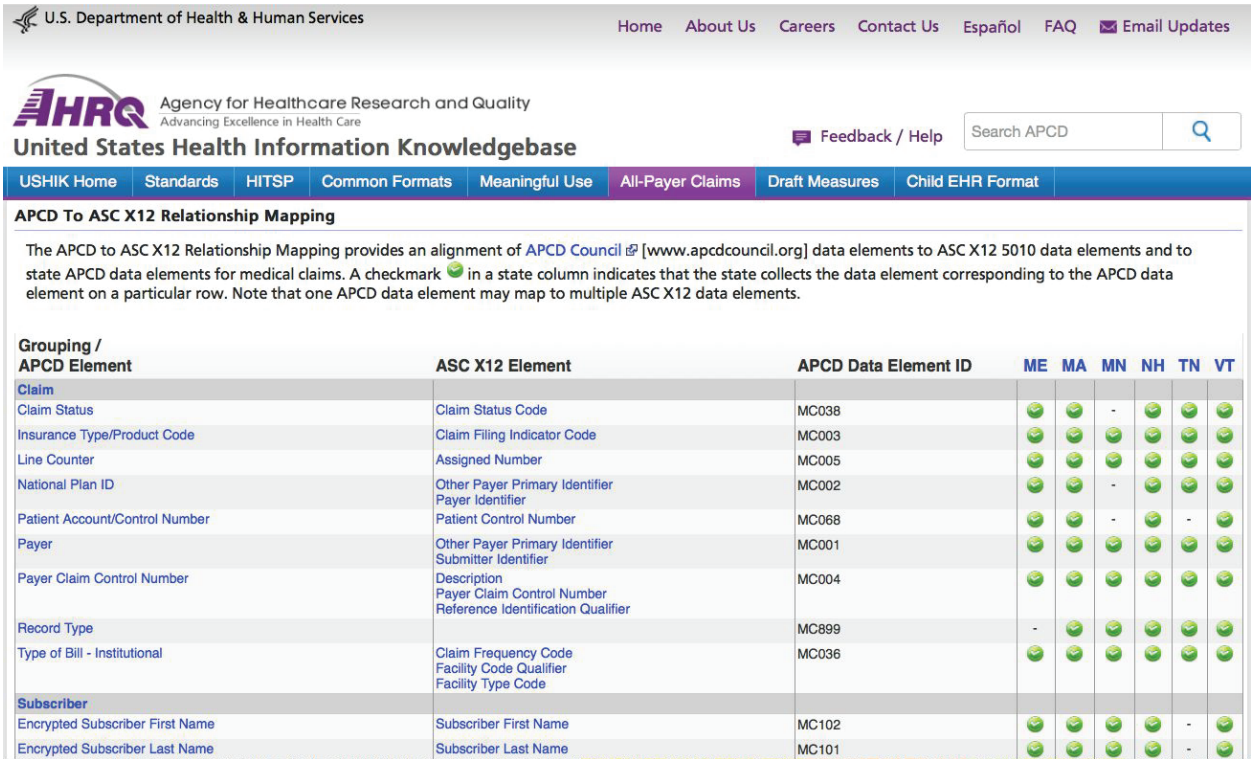
The APCD Council partnered with ASC X12 to develop the Post-Adjudicated Claims Data Reporting Guides (PACDR) to support professional, institutional, and dental claims data submission to state and federal agencies. Because the guides support many purposes, there are many more data elements in the PACDR guides than there are in the APCD Council core set of data elements, or any of the existing APCDs. However, the APCD Core is an important reference for selecting the appropriate data elements from the PACDR guides for building the APCD data system. For example, the Core names "rendering provider" as a core data element for the medical file. The referent standard for "rendering provider" in the PACDR guide is defined in a specific loop and segment as the provider that renders the services to the patient. "Rendering provider" and its associated metadata (e.g. code values, situational rules, etc.) are all defined in the PACDR.

While the ASC X12 implementation guides describe a transactional process, the trading partners (states and carriers) will need to determine whether the transactional format will be feasible for the state APCD or whether a flat file format will meet the needs. Regardless, the list of APCD Core set of data elements can be used together with the PACDR guides to create the data submission specifications for the APCD. In addition to ASC X12, NCPDP partnered with the APCD Council to develop the Uniform Healthcare Payer Data Standard to support reporting requirements for claims data submission to states or their designees.

USHIK APCD Portal

To assist states with traversing between the APCD Council core and the ASC X12 PACDR standard, the APCD Council partnered with AHRQ, Public Health Data Standards Consortium, and Washington Publishing Company (the publisher of ASC X12 guides) to develop the **APCD portal** on the United States Health Information Knowledgebase (USHIK). The portal also provides an indication of what states are collecting, vis-a-vis the Core set of data elements, as shown in Figure 3.

FIGURE 3: THE APCD PORTAL IN USHIK



Grouping / APCD Element	ASC X12 Element	APCD Data Element ID	ME	MA	MN	NH	TN	VT
Claim								
Claim Status	Claim Status Code	MC038	✓	✓	-	✓	✓	✓
Insurance Type/Product Code	Claim Filing Indicator Code	MC003	✓	✓	✓	✓	✓	✓
Line Counter	Assigned Number	MC005	✓	✓	✓	✓	✓	✓
National Plan ID	Other Payer Primary Identifier Payer Identifier	MC002	✓	✓	-	✓	✓	✓
Patient Account/Control Number	Patient Control Number	MC068	✓	✓	-	✓	-	✓
Payer	Other Payer Primary Identifier Submitter Identifier	MC001	✓	✓	✓	✓	✓	✓
Payer Claim Control Number	Description Payer Claim Control Number Reference Identification Qualifier	MC004	✓	✓	✓	✓	✓	✓
Record Type		MC899	-	✓	✓	✓	✓	✓
Type of Bill - Institutional	Claim Frequency Code Facility Code Qualifier Facility Type Code	MC036	✓	✓	✓	✓	✓	✓
Subscriber								
Encrypted Subscriber First Name	Subscriber First Name	MC102	✓	✓	✓	✓	-	✓
Encrypted Subscriber Last Name	Subscriber Last Name	MC101	✓	✓	✓	✓	-	✓

Quality Assurance Testing

As the data are submitted to the APCD, it is important to establish an automated quality control process. One such control process is use of a pre-processor that requires the data submission to be in the required format prior to submission. This function is developed by the data consolidator and distributed to the data submitters so they can format the data prior to uploading it to the APCD. The goal is to have cleaner, more consistent data prior to submission.

Other important core controls include data edits, error thresholds, and benchmarking. As data are submitted, field-level and quality edits are detected, ensuring that the data elements are populated, and the values of the data elements fall within reasonable limits. Over time, carrier-specific thresholds are often established by a state, after the state and the carrier review historical data together, to determine if there are unique characteristics that require carrier-specific thresholds. In addition to trend edits, reference checking may shed further light on data quality. Minnesota contracted with a vendor to run benchmark analyses against the vendor's claims database and the Minnesota APCD. Minnesota also uses the statewide hospital discharge data base as a reference database, benchmarking the APCD with the hospitalization data for validity checks.

After the data are submitted and consolidated, there are other quality assurance processes and methods that can be implemented, including:

- *Checks of the data that look for normal ratios and volumes of eligibility records and claims. This ensures that the ratios and volumes meet normal expectations. This review can help with understanding the claims and member volume of the submitting carrier. For example, some carriers may have little pharmacy volume compared to other carriers, which may be expected because the pharmacy claims are submitted by a PBM. This understanding of the insurance market can help explain what is expected in the data.*
- *Frequency distributions of values or field lengths, to review whether the values in individual fields meet expected values and field lengths (as detailed in the Data Submission Manuals).*
- *Calculation of per member per month (PMPM) claims dollar costs, by data submitter and/or by type of service, to look for consistency and wide variation in PMPM amounts, which can indicate a quality issue.*

- *Tests for interaction among payers, which can help detect duplicate submissions. For example, as previously described, a PBM might submit the eligibility records and claims for the same members that are being submitted by a carrier, creating the appearance of duplicate submissions.*
- *Tests for continuity and persistency in claims and eligibility can help detect gaps or unusual spikes and drops in the volume of records over time, for both eligibility and claims. For example, if the volume of eligibility records decreased from 20,000 members in October to 3,000 in November and then increased to 20,000 in December, this drop may warrant a conversation with the submitter about the unusual activity and potential need for resubmission of data.*

RFP Development

Because of the complexity of building an APCD, some state agencies/organizations elect to outsource the development and maintenance of the APCD, issuing a vendor Request for Proposal (RFP). To date, many states—including Maine, New Hampshire, Minnesota, Colorado, Connecticut, Rhode Island, Vermont, and Utah—have issued RFPs for the consolidation of claims data and construction of their APCDs. While there is much variation across the RFPs, there are commonalities in the components of the RFP.

RFPs typically include:

- *Introduction and background (which may include information about the statutory authority, the insurance market, number of covered lives, and potential number of data submitters)*
- *Purpose of the RFP (defining the role or functions of the awarded vendor)*
- *Goals and objectives of the RFP*
- *Scope of work (details about the role and activities to be performed by the contractor)*
- *Company summary (details about the company responding to the RFP)*
- *Financial proposal (budget for the implementation, maintenance, analytics and other services proposed)*

The scope of work requires detail about the responding vendor's intended approach to data compliance and data management, as well as editing and data fixes, and data warehouse and hosting services. The RFP may also include questions about the vendors' approach to updating APCD data submission rules, specifications, and resulting data submission processes. The scope of work also includes detail about expectations for file building, analytics, and requirements

around specific software (e.g., episode treatment groupers or diagnosis treatment grouper technology), and whether the costs for those tools will be borne by the contractor or the state. Table 6, based on an APCD Council White Paper about RFP Development, details RFP components.

TABLE 6: APCD RFP SCOPE OF WORK COMPONENTS

COMPONENT	KEY QUESTIONS/ISSUES
Data submission specifications	› Will the state require national standards (e.g., PACDR)? › Will additional state-specific fields be added? › Will the state create the data submission guides, or include this in the vendor scope of work?
Data compliance	› Will there be dedicated staff to continuously monitor compliance to submission requirements? › Is the data management system capable of tracking data supplier submissions and provide reports/feedback to each data supplier relevant to submission failures? › Will state staff monitor and assure compliance with each payer, or contract with the vendor to do this? › Does the state have internal capacity to manage the relationships with payers, or should this function be outsourced?
Data management	› Is the data management process and IT infrastructure sufficiently documented? › Are policies and procedures in place that address all aspects of the data management lifecycle with assigned responsibilities? › How will data quality be measured and improved?
Editing and data fixes	› Will the vendor utilize proprietary edit protocols? Are these documented in the data submission guide? › Will the vendor design standard payer data quality feedback reports? If so, how often? › Is the vendor prepared to address historical files and resubmissions of data, if data quality issues are identified?
Data warehouse/ hosting services	› Where will the data be stored? Within a state agency? With the vendor? Or a combination? › How will data access rights be assigned and monitored?
Update specifications	› Do processes align with the latest national standards for claims reporting? › How often will the processes be updated? › What will be the process be for implementing updates, and for communicating changes to data submitters?

TABLE 6: APCD RFP SCOPE OF WORK COMPONENTS CONT'D

COMPONENT	KEY QUESTIONS/ISSUES
Promote patient and provider linking across files, and the creation of provider directories	› What systems and methods will be used to develop provider directories? › Can this be done through the use of potential shared services with other data systems (e.g., HIX)?
File building and submission	› What files will the state require to be submitted? › In what format and timeframes are these to be submitted?
Analytics	› What analytic services are required? › Will the agency retain some analytic capacity or will all analytics be outsourced? › Are there analytic partnerships within the state that should be explored? › If outsourced, will analytic functions be in one RFP, in multiple RFPs, supplemented with state work, or some combination of all of those?
Data users	› What services will be provided to data users, if any? Custom reports? Standard extracts? What is the vendor's role and what is the agency's role? › Will the vendor provide training on the use of analytic tools? › Will the agency (or the vendor) convene user groups, establish electronic communications, or a combination of these methods to support data users?

Emerging Interest in Expanding Content of APCD

Many states have explored the prospect of expanding the APCD beyond information captured from claims payment systems. Examples cited by states include:

› *Non-claims based payments (e.g., performance payments, medical home payments)*
› *Plan benefit design*
› *Premium information*
› *Linkages to clinical or population health databases*

In many cases, it is clear that these data characteristics may have to be captured in supplemental data efforts and are not suited for inclusion directly into the claims system. For example, Massachusetts has been a front-runner in finding ways to gather non-claims based payment data and published some of their work related to Alternate Payment Methods.

Information about the member plan benefit design holds the potential of filling a gap in the understanding of what benefits are available to the member and would allow analyses examining outcomes due to benefit design. Payers have indicated that the storage of plan benefit design information is not easy to access. Typically, a payer offers an enormous number of benefit and plan design combinations, and there are no standard coding schemas for these data. More about non-claims based payments and plan benefit design is documented in a report commissioned by the Maryland Health Care Commission.

Many states have expressed interest in linking their APCD with other data sets including vital records (e.g., Utah, Colorado, and Vermont), cancer registry (e.g., New Hampshire), and or clinical data (e.g., Maine). When considering the technical build of the APCD, it is important to consider the use case for linking to other data sets. These planned uses may require direct identifiers or probabilistic linkage to other data sets, and those data elements would need to be included in the APCD design. The linkage may also require specific legislative language, administrative rules, or policies.

Conclusion

The construction of state APCDs is complex and resource-intensive, warranting careful planning with all stakeholders. The technical build planning process starts with careful consideration of what the desired outputs are for analyses and reporting. From there, the planning process works backward to determine what must be included in the APCD technical build requirements. Factors include:

- *The health insurance market in the state as it relates to the potential number and size of data submitters*
- *Type of data files to be collected*
- *Determination of the inclusion of public payers*
- *Data element definition and formats*
- *Data submission schedules*
- *Quality assurance processes*

On a more granular level, the data elements and formats must be defined, and the data submission schedule and quality assurance protocol developed. In the event that a state opts to contract for the technical build of the APCD, many of these considerations will have to be defined in the RFP.

The existing APCD states can be helpful resources to those states considering building an APCD, given their experience with data submission rules and vendor RFP administration.

TECHNICAL BUILD ASSESSMENT CHECKLIST

STEP	WORKSHEET/TOOL	COMPLETE
Develop the Data Submission Parameters for the APCD: › Volume and size of submitters › Types of sizes of files › Data elements › Schedule of reporting › Quality assurance protocols	Technical Build Assessment - Data Submission Guide Worksheet	
Review the technical build activities, and identify the approach to address the activities	Technical Build Assessment – Development Activities/ Resources Worksheet	
Identify the need(s) for RFP(s), and develop a RFP language, as needed	Technical Build Assessment – RFP Development Worksheet	

SECTION 5:

Analysis and Applications Development

States develop APCD reporting systems to fill critical information gaps, promote health care transparency initiatives, and provide actionable information for their stakeholders. Although states vary in their reporting priorities and APCD approaches, the value and sustainability of any APCD system is closely linked to the information it provides to inform consumer, policy, market, and research decision-making.

Learning Objectives:

- How and when should a state develop its analytic plan?
- What are the components of an analytic plan?
- How can states approach public reporting of APCD data?
- How can states reduce risks related to data release?

APCDs strive to balance the three principles of data policy:

- *Transparency and public availability*
- *Utility of the data for multiple uses and users*
- *Data safety*

All three principles must be in balance to fully realize the potential of an APCD system. If one of these principles is over-emphasized at the expense of the others, the public good is not served. Therefore, comprehensive policies that are consistent with HIPAA, HITECH, and a plan for guiding data use and access, are essential to assure this balance.

Analytic Plan

As discussed in Section 1. Engagement, documenting stakeholder information needs through a use case development process is a critical step in APCD development, and should occur early in the process. A preliminary analytic

plan developed before data collection begins and refined as the APCD system matures and evolves can be very valuable to states as they develop their APCD. The analytic plan provides the "business case" for the APCD and helps manage expectations by documenting various stakeholder priorities.

The analytic plan guides the data analytics and release processes, specifically:

- *What information, if any, will be shared*
- *With whom data reports will be shared*
- *When data and reports will be shared*
- *Restrictions to public release and access*
- *In what formats will data be released (e.g., data files, web sites, reports)*

More specifically, the analytic plan can serve as a platform to consider and make plans to address a number of key issues about the APCD that impact the analysis. Several of these key considerations are in Table 7.

TABLE 7: COMPONENTS AND CONSIDERATIONS OF AN APCD ANALYTIC PLAN

OBJECTIVE	CONSIDERATIONS
Document the policies and process for data collection, analytics, and release that are consistent with the APCD governance structure	› Are there restrictions to uses and access? › Are there rules or mandates about who can access the data? › Will access to APCD data be permitted, and to whom and under what conditions? › Does the law mandate certain reports or applications (consumer websites)? › Are data release fees established; if not, how will they be set?
Define the stakeholder engagement process for all stages of the analytic process: planning, implementation, release	› How will stakeholder input be assured initially and on an ongoing basis? › How will individual stakeholder views be managed? › What process will be used to manage disagreements or concerns? › Will there be technical advisory groups for various aspects of the data collection, analytic, release cycle?

TABLE 7: COMPONENTS AND CONSIDERATIONS OF AN APCD ANALYTIC PLAN CONT'D

OBJECTIVE	CONSIDERATIONS
Establish a process for continuous data quality assessment, improvement, and validation	› What is the plan to assess data quality and how to address issues that are identified? › How will the downstream implications of data quality issues be handled? › Is there a plan to provide carrier feedback and improvement targets? › Is there a review and validation period prior to the release of public reports?
Document the dissemination plan that balances privacy protections with data utility	› What is the data oversight process and how will release policies be established and conducted? › Will there be data use agreements for some data sets? Which ones? › Is there a plan for disseminating APCD data, reports? › Is the process for requesting and obtaining data transparent and equitable to different users (e.g., public, researchers)? › What statistical modifications will be implemented to mask identifiable data? › Is there a review and validation period prior to the release of public reports?

The Role of a Technical Advisory Group

APCDs often establish a technical advisory, data user, or other group of stakeholders to guide solutions to the numerous political and technical issues associated with public reporting and release. These advisory groups counsel the agency on the appropriate and effective use of data and assist in the many decisions that must be addressed in order to produce quality analytics and applications. A technical advisory group may not be a policy making group, but rather a gathering of experts focused on developing the analytic path forward. Many of the questions in the analytic plan (Table 7) can be vetted and addressed by this group. Invitations to stakeholders should make clear the nature and limitations of the advisory group.

Experts in statistics, claims data, applications, data display, user experience, risk adjustment strategies, and the like provide valuable input into the group. Maine's Data User Group is made up of many data users, convened regularly by the Maine Health Data Organization to share data findings, methods, and results. Similarly, Massachusetts convenes a Technical Workgroup for its data users. This

work has created an evolving user community to support more effective use of the APCD data. The agency will also want to consider a process for managing data requests in an open, transparent manner that assures equity in the decision making process. For example, the Maine Health Data Organization has an online data request portal and publicly posts all requests and their review status.

APCD Reporting and Measurement

As previously discussed, states with APCDs have developed a broad range of use cases for APCD data. Many of these are showcased on the ACPD Showcase website. Within all of the use cases, major categories of analytic measures can be defined. Table 8 provides examples of measures within those categories.

TABLE 8: EXAMPLES OF APCD REPORTS AND MEASURES BY CATEGORY

MEASURE CATEGORY	EXAMPLE REPORTS AND MEASURES
Health Care Utilization	› Overall utilization, with analysis results by payer groups, geographic areas, service lines (e.g., Health Maintenance Organizations, Preferred Provider Organizations, etc.) › Service type utilization, in categories, such as inpatient, outpatient, ED, observation, specialty, primary care, pharmacy, imaging › High-level views of variation in prescription drug utilization and spending
Health Care Costs	› Percentage of total health care costs for top disease conditions › Total cost for procedures (e.g., knee arthroscopy, lower back MRI, etc.) and conditions (e.g., depression, diabetes, etc.) › Cost by payer, including PMPM costs, high cost conditions, profile reports on medical, dental, pharmacy costs, plan payments, plan costs by procedure › Cost to patients, including total out-of-pocket cost, co-pays, co-insurance, deductible amounts › Episode cost, costs by chronic conditions or other episodes of care › Pharmacy costs, including highest cost and highest frequency pharma-ceuticals › Total cost of care, per member per month at the clinic or group level
Population Health	› Prevalence and incidence of key chronic conditions › Standards of care for key chronic conditions (e.g., hemoglobin A1c among people with diabetes) › Geographic variation in key chronic conditions
Quality	› Preventative care screening rates by geography or health plan › Hospital re-admission rates by hospital or geography › Hospital re-admission rates by procedure

Several states have adopted a staged or tiered approach to release of analytic products and measures. Beginning with statewide or sub-state measures before the release of more granular analysis (e.g., by provider or payer) is an approach that serves several purposes:

- *It provides assurance to stakeholders that there is a clear process and set of outcomes for the APCD analytics.*
- *It provides opportunities to generate experience early on with the data and demonstrate APCD value with basic, more global measures.*
- *It highlights data deficiencies and priorities for improvement before moving on to more complex, more sensitive, and more granular measures.*

In states with mandates for public reporting of comparative cost, price, and quality information by provider, there are typically political and technical challenges that must be addressed. As previously discussed, there may be sensitivities in publishing negotiated discounts between payers and health care providers, and states need to decide how to handle the release of analysis that might disclose those discounts. Some states release that information, while others may mask the actual rates using statistical techniques. For public reporting at the payer and/or provider level, states have found that a review and validation period during which payers and providers who are named in the reports are allowed to provide comments and corrections on the results have been valuable. Public reporting initiatives also need to consider when results will be suppressed, due to small sample sizes or privacy concerns. As described in Section 4: Technical Build, public reporting of Medicare and Medicaid data generally has to adhere specific protocols for data release, which often have guidelines for suppression that can guide a state's public reporting initiatives.

Data Use and Release

The agency's analytic plan should lay out the data products and formats stakeholders need to meet their information needs. Aggregate, structured reports pose few privacy risks, but they may not meet the needs of many users who plan more sophisticated analyses. Some states will release more detailed data products, such as public use files that have been de-identified through statistical modification and suppression of identifiers. Agencies typically

accompany the public use file release with a DUA that stipulates the terms for data use, handling, re-release, and restrictions. States typically refer to HIPAA standards to identify sensitive data fields and adhere to the rule of only releasing the minimum necessary data to meet the analysis needs. DUAs often include penalties for inappropriate use and disclosures. More granular research (or limited use) data files can also be released, generally through a formal application process. A DUA is typically required for those releases as well. In addition, as previously mentioned, a data release committee is typically defined by a state (often in statute) to review all applications for data to ensure that the data uses are appropriate and the data safeguards are demonstrated by the applicant.

Conclusion

The ultimate value of an APCD system is the unique information it provides to its key stakeholders. Local stakeholder needs should be a key factor in the design of the system, and appropriate privacy and security controls should be in place, guiding the release process to protect the confidentiality of the data. A comprehensive analytic plan with a transparent and open process for providing data at various levels of detail for key user types is important to assuring that APCD data are used appropriately and safely. States are proving that it is possible to provide cost-effective, useful information to multiple stakeholders while protecting the underlying data.

ANALYTIC PLAN ASSESSMENT CHECKLIST

STEP	WORKSHEET/TOOL	COMPLETE
Develop a comprehensive analytic plan	Analysis and Application Development - Analytic Plan Worksheet	
Develop DUAs for data release	Analysis and Application Development - Data Use Agreement Worksheet	
Develop a data release plan	Analysis and Application Development Assessment – Data Release Considerations	

SECTION 6:

Feedback Loops and Continuous Engagement

As emphasized throughout this manual, stakeholder engagement is critical in APCD design, construction, and the production of meaningful information. Each stage of the APCD lifecycle, from planning to public reporting, relies on interdisciplinary stakeholder communication. This engagement assures that the system yields the highest value and ultimately serves the members of the stakeholder community.

Learning Objectives:

- Why is APCD development a continuous process?
- How does a state define and ensure adequacy of continuous feedback loops?
- What success factors should a state consider, and how will they evaluate the effectiveness of their APCDs?

Continuous Engagement

Engaging stakeholders is much more than holding meetings and issuing periodic updates. It requires an initial and evolving vision that reflects the values of the stakeholder community and an ongoing commitment of staff time and resources. States that have invested in building strong stakeholder processes have forums to deliberate the many challenges faced during each phase of system development and deployment. As APCD programs and systems mature, stakeholders provide input for enhancements that drive the ultimate value of the information produced.

States often convene their stakeholder groups on a quarterly or semi-annual basis to provide updates about the system and present any implementation challenges. As the system evolves, reassessment of the stakeholder representation is important to determine whether additional members need to be invited to participate in the group.

In addition to the large stakeholder group, shorter-term subcommittees or technical advisory groups are often established to address specific issues. For instance, a specific sub-group might propose data access and release processes. As discussed in Section 5. Analysis and Application Development, several states convene data user groups, populated with data requestors, to specifically share the experiences, quality, and analyses of the data. This process allows users of the data sets-- often local researchers and practitioners-- to share data analysis methods, strategies, and findings in a common forum documented for future users.

Key Success Factors

While every state APCD experience is unique, the state experiences to date have identified a number of key factors to establishing and maintaining a successful APCD. These factors typically include the following:

Inclusiveness

While obvious, a key success factor to a successful stakeholder process is inclusiveness. This takes time and work to bring everyone together to shape a shared vision, then to communicate said vision more broadly to build support for the effort. Ideally, all stakeholder groups are invited and are represented. Excluding one group to facilitate or expedite a decision or move the process along often backfires, causing delays later in the process as the excluded stakeholder raises challenges to decisions.

Transparent and Open Process

Achieving a shared vision or consensus on technical decisions is arduous work. Consensus does not mean that all stakeholders agree on every point or decision; it means that all of the issues and/or concerns are discovered, considered, and deliberated. Development of a definition of consensus is a useful exercise as

working groups begin their process. Decisions reflect the inevitable trade-offs that must be made when building an information system. The discussions leading to decisions need to be conducted openly, explained clearly, and documented thoroughly.

Managing Stakeholder Expectations

States have learned that it is easy to capture stakeholder excitement in the early stages of the APCD development. APCDs provide essential cost and utilization information not generally available elsewhere nor seen before. There are many overlapping interests among industry, policy, employers, researchers, and consumers. However, as stated before, this initial energy may wane during the lengthy technical build process, so the stakeholder process should be designed accordingly. Gaining support for valuable information for various applications is essential. Yet, technical problems, privacy concerns, and other challenges will arise and must be addressed, and an expectation for compromise and a realistic timeline are essential.

Feedback Loop

The stakeholder process must be sustained throughout the life of the APCD program, from planning to improvements. APCD development is cyclical and iterative. Stakeholders provide the context for the APCD and provide keys to understanding the information the APCD produces. Providing continual feedback to stakeholders about the system can help maintain the engagement. To accomplish this, states have found that developing and maintaining a work plan has been effective in providing updates as the development progresses. Adjustments to data collection, analytics, and release are made based on stakeholder feedback and input.

Table 9 provides key dimensions of a successful APCD work plan, which incorporate aspects of project management to guide large-scale systems development.

TABLE 9: APCD WORK PLAN CONSIDERATIONS

TASK	CONSIDERATIONS
List the vision, goals, objectives, and primary tasks	› Does the plan incorporate the mandated mission and objectives contained in the law (or system charter)? › Does the plan reflect the shared values of stakeholders?
Establish a process and timeline with milestones for making key decisions, and what defines consensus amongst stakeholders	› What is the leadership structure? › Is there a clear process for reporting progress and technical issues and gathering input? › How will disagreements be aired and resolved?
Define the work plan elements and accountability for each element	› List action steps and tasks and dependent relationships. › What are vendor roles/responsibilities? Agency roles/responsibilities? › Where does accountability for complete of tasks begin and end? › How do variances and technical problems get resolved?
List the resources available and needed	› Manage expectations by clearly denoting funding and staffing constraints. › How will the APCD infrastructure be designed (vendor, in-house, hybrid)? › Is the infrastructure aligned with stakeholder information needs? › What community partnerships/shared service arrangements can be leveraged?
Update and communicate plan status regularly	› Keep the work plan updated. › Communicate progress and issues to the stakeholder group in a timely way. › Adjust the plan as needed to accommodate technical changes and reflect lessons learned.

States have developed communications strategies to relay continual feedback. These strategies are closely tied to the work plan and are typically managed by the stakeholder group leader. Many states post all work products, specifications, decisions, and data requests on their public agency website. This is a cost-effective way to share decisions with all stakeholders. Reporting to a state agency or legislative oversight committee can also be effective. However, the websites and communications, while important, cannot replace the diligence of in-person stakeholder engagement. These stakeholder relationships and stakeholder

commitment ("skin-in-the game") will be the backbone of any successful APCD program. Planning for the communication to stakeholders should be part of the APCD development process. Considerations for a communication plan are listed in Table 10.

TABLE 10: APCD COMMUNICATION PLAN CONSIDERATIONS

TASK	CONSIDERATIONS
Define the communication channels	› What combination of engagement strategies are appropriate and available? › Are the various strategies aligned (i.e. in-person meetings, publications, and websites)?
List and define the roles of the stakeholders	› Define the structure, roles, and expectations for the stakeholders and create a documented decision making process. › Develop a process for changing the stakeholder group composition over time, and communicating those changes. › Consider the need to add subcommittees to the stakeholder structure, and be transparent about the structure being created.
Define the problems and describe solutions and trade-offs	› Describe the task or decision that needs to be addressed. › Explain and document options and decisions that have been debated.
Lay out a plan for stakeholder communications, venue, and frequency for meetings	› Document stakeholder communication checkpoints in the work plan. › Determine appropriate level of interaction (e.g., email or in-person meetings) for the message being communicated or the topic being discussed. › Periodically evaluate the effectiveness of the communications plan and stakeholder engagement, making adjustments as needed.

Conclusion

Stakeholders are the foundation of statewide APCD programs, guiding the vision and implementation decisions. Stakeholders represent the constituencies for the APCD data and provide the environmental context for its use, and they guide decisions about trade-offs that must be made as the data system evolves. A deep understanding of the data and the information that can be derived by all

stakeholders is what ultimately creates stakeholder value. In addition, the state entity responsible for the APCD development will have to invest resources to keep stakeholders engaged and push the APCD forward, balancing a range of inputs and interests.

Trust is the key element of APCD development. It is derived from a feeling of inclusiveness, transparent and open processes, and ongoing feedback. Sustaining a robust stakeholder process is a challenge, especially with staff and resource challenges, but it is an investment that results in the ultimate success of a statewide APCD program.

States have found that, in addition to their internal state processes, cross-state collaboration has been invaluable. There is much to be learned from state sharing of challenges, solutions, and approaches to APCD development.

FEEDBACK ASSESSMENT CHECKLIST

STEP	WORKSHEET/TOOL	COMPLETE
Develop work plan for continual engagement	Feedback Loops and Continuous Engagement Assessment - Work Plan Worksheet	
Develop communications plan	Feedback Loops and Continuous Engagement Assessment – Communication Plan Worksheet	

APPENDIX

Worksheets

Section 1: Engagement Assessment

Use Cases Worksheet

List use cases below. The **APCD Showcase** provides use case examples, for reference.

USE CASE EXAMPLE	USE CASE DESCRIPTION	AUDIENCE	SUPPORTING DOCUMENTATION (EXAMPLES, ANTICIPATED DESIGN, ETC.)
Ex. Consumer Website	Our State will utilize claims data to build a website for consumers to compare prices of select medical procedures.	Consumers	Consumer_Website_Plan.pdf

Section 1: Engagement Assessment

Stakeholders Worksheet

List stakeholder members with contact information and interest in the APCD below. This list will evolve over time.

TYPE OF STAKEHOLDER	STAKEHOLDER	EMAIL	PHONE	INTEREST IN APCD
Ex. Policy maker	Senator John Doe	johndoe@somestate.gov	###-###-####	John is interested in the APCD with a focus on consumer tools.

Section 1: Engagement Assessment

Data Efforts Worksheet

Identify current and planned state data efforts that might relate to APCD development activity.

DATA EFFORT	DATA EFFORT DESCRIPTION	INTEREST IN APCD	STATUS
Ex. Health Insurance Exchange	The state is operating a health marketplace exchange (HIX).	Common need for provider and patient directories	Initial conversations to outline common needs complete

Payer and Market Assessment Worksheet

Identify the payers (public and private) in the state, with assessment of market share.

COMMERCIAL DATA SOURCES

PAYER	PAYER FEEDS	COVERED LIVES	MARKET SHARE	COVERAGE TYPES	PAYER DESCRIPTION	STATUS
Ex. United Healthcare	20	100,000	20%	Medical, pharmacy and dental	Largest payer in the state. Will have medical, eligibility, pharmacy claims. A United representative is in the stakeholder group.	Submitting to APCD

MEDICAID, MEDICARE, AND OTHER DATA SOURCES

PAYER	PAYER FEEDS	COVERED LIVES	MARKET SHARE	COVERAGE TYPES	PAYER DESCRIPTION	STATUS
Ex. Medicaid	1	100,000	20%		We are working with the state Medicaid office to obtain these data.	Developing MOU

Legal Barriers Worksheet

List potential legal barriers in your state below and document potential strategies for overcoming the barriers described.

LEGAL CONCERN	LEGAL BARRIER DESCRIPTION	APPROACH
Ex. HIE-APCD Linkage	There is interest in the state and amongst the stakeholder group to link the HIE, when developed, and APCD. This will potentially help with linking clinical and cost information. Technical and legal barriers exist in the linking of the data.	Consultation with legal team to better understand privacy and security concerns of linkage - review with stakeholder group; Consultation with in-house APCD and HIE analysts to better understand technical barriers for linkage - review with stakeholder group.

Section 2: Governance Assessment

Governance Considerations Worksheet

Track the decisions about the major governance considerations below.

GOVERNANCE CONSIDERATIONS	SUPPORTING DOCUMENTATION APPROACH	
Will the system be voluntary or mandated?	Ex. Mandated	Ex. Consensus of steering committee or draft legislation
Identify the authority or authorities to collect the data		
Status of development of legislation, if applicable		
List purpose statement		
Identify governing body and oversight plan		
Document intended scope of data collection		
Document the privacy and confidentiality concerns, and plans to address them		
List the funding considerations (more detailed funding documentation is in the Funding Sources Worksheet)		
Document the reporting requirements		

Section 2: Governance Assessment

Rules and Regulations Considerations Worksheet

Identify the status of rules and regulation components for the APCD. This should be cross-referenced with the detail documented in the **Technical Build Assessment - Data Submission Guide Worksheet** and **Analysis and Application Development - Data Release Considerations Worksheet**.

RULES AND REGULATIONS CONSIDERATIONS	SUPPORTING DOCUMENTATION	
Status of development of data submission rules	Ex. Being drafted, last modified in January 2014	Ex. Draft Data Collection Rules.doc
Status of development of data release rules and/or policy		
If governance is a non-state entity, have the necessary interagency agreements been established?		
If applicable, have Memorandums of Understanding (MOUs), Data Use Agreements (DUAs), and/or other agreements been established to allow collaboration across state entities?		

Board Compositions Worksheet

Identify representative members of the APCD program privacy, advisory, or other boards

ADVISORY BOARD

NAME	AGENCY REPRESENTATION	EMAIL	PHONE	TYPE OF STAKEHOLDER	ROLE
Ex. Jane Doe	Ex. Medical Society	jdoe@StateMed.org	###-###-####	Provider	Advise on data use protocols

PRIVACY BOARD

NAME	AGENCY REPRESENTATION	EMAIL	PHONE	TYPE OF STAKEHOLDER	ROLE
Ex. John Doe	Department of Health	johndoe@somestate.gov	###-###-####	State Agency	Represent health department authorities and release protocols

OTHER

NAME	AGENCY REPRESENTATION	EMAIL	PHONE	TYPE OF STAKEHOLDER	ROLE
Ex. John Doe	Department of Health	johndoe@somestate.gov	###-###-####	State Agency	Represent health department authorities and release protocols

Section 3: Funding Assessment

Funding Sources Worksheet

Identify the funding sources, actual and potential, below.

CURRENT FUNDING OPPORTUNITIES

FUNDING SOURCE	START-UP OR CONTINUAL FUNDING	BUDGET	TIMELINE	STATUS
Ex. General state appropriations	Continual	$1,000,000 per SFY	Through 2020	Approved

POTENTIAL FUNDING OPPORTUNITIES

FUNDING SOURCE	START-UP OR CONTINUAL FUNDING	BUDGET	TIMELINE	STATUS
Ex. CIIO Grant	Start-up	$1,000,000	CY 2015	To apply

OTHER POTENTIAL RESOURCES

RESOURCE	DESCRIPTION
Ex. University Institute Partner	The insurance department has a relationship with a local university analytics shop which could provide assistance with analytics support as part of current contract.

Data Release Pricing Worksheet

Describe plans for the distribution of research data files and applications and the structure of pricing, if applicable.

DISTRIBUTION PLAN	STATUS
Ex. Our state will include structure in data release rule and post fee structure to our APCD website (stateAPCDwebsite@state.gov).	Ex. Applications in development

DATA FILE	PRICING	STATUS OF APPLICATION	SUPPORTING DOCUMENTATION
Public Use File	Ex. Tiered based on organization type (Non-profit, redistributor, commercial entity). See data release rule.	Ex. In development, last draft January 2014	Ex. Draft public use file.doc
Limited Use File	Ex. Tiered based on organization type (Non-profit, redistributor, commercial entity). See data release rule.	Ex. In development, last draft January 2014	Ex. Draft limited use file.doc
Custom Reporting	Ex. To be determined based on application needs	Ex. In development, last draft January 2014	Ex. Draft custom report application.doc
Interagency sharing/ release			

Data Submission Guide Worksheet

Identify considerations for inclusion in data submission documentation.

VOLUME AND SIZE OF SUBMITTERS	
List Data Submitters (Refer to Market Assessment Worksheet)	Data Submitter: Thresholds: Reporting Waivers: Data Submitter: Thresholds: Reporting Waivers: Data Submitter: Thresholds: Reporting Waivers: Data Submitter: Thresholds: Reporting Waivers:
TYPES AND SIZE OF FILES	**ANTICIPATE FILE SIZE**
Claims Medical Dental Pharmacy Other	
Eligibility Medical Dental Pharmacy Other	
Provider	
Other	

DATA ELEMENTS	PLANS FOR COLLECTION
Will your state be using the PACDR standard for data submission? If not, what format and does it align with other state/national standards?	
Will your state be using the NCPDP standard for data submission?	
SCHEDULE FOR REPORTING	**LIST SCHEDULE(S)**
Has a schedule for reporting been developed?	
QUALITY ASSURANCE PROTOCOLS	**LIST EDITS AND PROTOCOLS**
Define quality assurance protocols	

Section 4: Technical Build Assessment

Development Activities/Resources Worksheet

Identify resources for APCD system technical build components.

	IN-HOUSE OR VENDOR	INTERNAL RESOURCES NEEDED (FTE AND ROLE)	RFP (Y/N)
Development of Data Submission Guide			
Data Collection and Aggregation			
Data Editing/Quality Assurance			
Data File Creation			
Data Analytics			

Section 4: Technical Build Assessment

RFP Development Worksheet

Identify the components needed for an RFP.

RFP DEVELOPMENT COMPONENTS	
Introduction and Background	
Purpose of the RFP	
Scope of work › Data submission specifications › Data compliance › Data management › Editing and data fixes › Data warehouse/ hosting services › Update specifications › Promote patient and provider linkages › File building › Analytics › Data user support	
Company summary	
Financial proposal	
Other	

Analytic Plan Worksheet

Identify the components of a comprehensive analytic plan.

ANALYTIC PLAN CONSIDERATIONS	DOES THIS APPLY? (Y/N)	SUPPORTING DOCUMENTATION
Identify data use and/or release requirements (e.g., must develop a transparency website as a stipulation of grant funding)		
List restricted uses of the data (e.g., prohibitions against revealing actual paid amount)		
What is the plan for analytic file warehousing and system architecture? (e.g., vendor, in-house, cloud)		
Is there a specific group guiding the development and implementation of data analytics and public reports? (e.g., a technical workgroup with committee bylaws)		
Will analysis functions be done in-house, via a vendor contract, or both? (e.g., what is specified in an RFP?)		
Will the tools for APCD analysis align with other stakeholder tools? (e.g., will the groupers used be common across the APCD and other stakeholders)		
What measures are planned for analysis? Will the state use only standardized measures, develop state-based measures, or use a mixed approach? (e.g., National Quality Forum endorsed measures)		
What are the intended release options for APCD analyses? Will reporting be done in phases? (e.g., Website, standard reports, custom reports, public use and research files)		
What is the review and validation process (e.g., for payers and providers) for reporting? (e.g., 45-day review period for analytic reports)		

Data Use Agreement Worksheet

Identify the components for an APCD Data Use Agreement. Note also the plans for pricing structure for data release in the **Funding Assessment - Data Release Pricing Worksheet**.

APCD DATA USE AGREEMENT	APPROACH	SUPPORTING DOCUMENTATION
Document the authority to release APCD data (e.g., statute, regulations)		
Define the authorized uses and restrictions of public, limited, or other use files and restrictions (e.g., cannot be re-transferred and no attempt to re-identify/link with other files).		
Document the legal and financial penalties for inappropriate disclosure or use of the public or limited use files (e.g., sanctions, or preclusion from acquiring data in the future)		
Openly state and document the methods data requests, reviews, and data release determinations (e.g., defining the release committee and application protocols)		
Data source and data agency review and citation requirements (e.g., the agency and/or data source must be cited in publications; the agency must review results before publication)		

Data Release Considerations

Identify options for release of APCD data.

APCD DATA RELEASE CONSIDERATIONS	APPROPRIATE FOR THE STATE? (Y/N)	SUPPORTING DOCUMENTATION
Structured reports: Reports are released that are designed to meet common data requests, and do not require the release of personal health information (PHI). (e.g., DRG market report with facility and claims mapped into date of service)		
Custom reports: Reports created specifically for a user, to address issues not covered in standard reports. Agencies will typically charge for these reports. (e.g., a special analytic report for an employer group or provider system)		
Web query systems: Interactive data bases that permit both public users and authorized users to build their own query from a defined analytic file. (e.g., **NH HealthWRQS claims module)**		
Transparency website: A specific web-based tools that posts prices (averages or medians, typically) for common procedures by facility and/or payer. (e.g., **Maine Health Cost)**		
Public use file: A de-identified, micro-data file which encrypts, aggregates, and suppresses direct and indirect identifiers. Typically released with a Data Use Agreement.		
Limited use or research file: A research-oriented data set, micro-data file that may retain some of the direct and indirect identifiers (such as date of service, date of birth) for qualified, reviewed, approved research with appropriate restrictions/ constraints. Typically released with a detailed Data Use Agreement and review committee approval process.		

Work Plan Worksheet

Develop an APCD work plan to assist with state's management of development process.

APCD WORK PLAN CONSIDERATIONS	SUPPORTING DOCUMENTATION
List the vision, goals, objectives, and tasks for the work plan for document the plans for the APCD development	
Establish a process and timeline for making key decisions with stakeholders	
List the resources available and needed for each major component of the APCD development process	
Identify accountability for each task	
Create a shareable document that can put into the public domain to promote the open and transparent process	
Update and share on a regular basis, with time allotted for communication with stakeholders (see the Communication Plan Worksheet)	

Section 6: Feedback Loops and Continuous Engagement Assessment

Communication Plan Worksheet

Identify the plans for long-term communications with stakeholders.

APCD COMMUNICATION PLAN CONSIDERATIONS	SUPPORTING DOCUMENTATION
Define the communication channels	
List and define the roles of the stakeholders	
Define the problems and describe solutions and trade-offs	
Lay out a plan for stakeholder communications, venues, and frequency for meetings	

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