All-Payer Claims Databases An Overview for Policymakers

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Introduction

Depending on the state or jurisdiction, between 8 percent (District of Columbia) and 20 percent (West Virginia) of gross state product (GSP) is spent on health care. From 1991 to 2004, the average annual percent growth in health care expenditures per capita in the United States was 5.5 percent with higher rates in some states (e.g., 7.8 percent in Maine).² While these spending figures are frequently reported, relatively little is known about what comprises these expenditures. Gaps in that knowledge limit the ability to identify opportunities to address rising health care costs. In response to this lack of transparency in health care spending, states are actively seeking robust information about the costs and performance of their state's health care delivery system. One key source of information to support transparency and general knowledge of the health care marketplace is the development of All-Payer Claims Databases (APCDs).

APCDs are an emerging data source to fill critical information gaps as policymakers and industry leaders seek solutions for transforming health care delivery. The number of states implementing statewide APCD initiatives has increased from a handful in 2005 to more than a dozen today. APCDs can provide information needed to develop health care reform efforts that are designed to address spiraling health care costs, expand access to care, and improve public health. To determine new mechanisms for the reimbursement of health care, it is important to understand the current costs associated with various services, providers, and facilities; the frequency of having those services provided; where care is typically delivered (e.g., physician offices, emergency rooms); and how care aligns to best practice recommendations.

States have used APCD analyses to answer questions in each of these areas. For example, states have used APCD data to:

 Develop a tiered-network insurance product for the small group marketplace (New Hampshire);

- Provide cost information to support consumer-driven health care choices, providing information about the varying cost of procedures in different medical facilities (Massachusetts, New Hampshire, Maine);
- Help employers understand variations in the cost and utilization of services by geographic area and in different provider settings (Maine, New Hampshire);
- Explore the value equation (cost and quality) for services provided (New Hampshire);
- Inform the design and evaluation plan of payment reform models including the medical home model and accountable care organizations (Vermont, New Hampshire);
- Evaluate the effect of health reforms on the cost, quality, and access to care in a state (Vermont, Maryland);
- Compare the prevalence of disease across a population (New Hampshire, Utah);
- Compare utilization patterns across payers to inform state purchasing decisions for programs such as Medicaid (New Hampshire) and to identify successful cost containment strategies (Vermont, New Hampshire);
- Determine payer competitiveness within the commercial insurance market (New Hampshire); and
- Estimate the cost of potential legislative changes affecting health insurance and later calculate the actual cost and impact of the legislation.

States with APCDs are providing a roadmap for implementation that other states can apply, making it feasible for almost every state to establish an APCD reporting program in the future.

Making the Political Case

The health care reform debate is happening and All-Payer Claims Databases must focus on the value of the information for reform. Health care markets are regional rather than national, so states must lead the way and work together to advance all stages of APCD development, including:

- Aggregation across markets and states
- Translation into actionable information
- Applications/use to improve decisions
- Enhancement of APCD through linkage of claims with clinical data

Source: Gov. Michael O. Leavitt NAHDO/SCI APCD Meeting, October 14, 2009

This brief provides an overview of statewide APCDs and covers the following topics:

- What are APCDs?
- In what states do APCDs currently exist and what states are exploring APCDs?
- Why develop APCDs?
- Who are the stakeholders of APCD systems?
- What are the major concerns or challenges related to APCDs and how they have been addressed?
- How are states using APCD information?
- How are APCDs governed and funded?

What are APCDs?

APCDs are large-scale databases that systematically collect health care claims data from a variety of payer sources. Statewide APCDs are:

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. In states without a legislative mandate, there may be voluntary reporting of APCD data.

МТ ND OR ID WY NE NV IL СО KS MO NC ΑZ OΚ AR SC NM

ΤX

Figure 1: Status of All-Payer Claims Databases as of May 2010

APCD systems have generally been developed in one of two ways: legislatively mandated data collection systems; or private and voluntary data collection. Although there are exceptions, most state-mandated programs require data submission from all payers with penalties for non-compliance. In state-based systems, information is typically made available to the general public at no or low cost with appropriate restrictions on data release. Private APCD initiatives typically rely on voluntary participation and are more likely to limit data release to subscribers and members. Thus, the greatest differences between a public and a private APCD are around mandatory data submission and public access and data reporting. Voluntary initiatives may be more flexible in their operations and provide important information to their participants, but may not meet the needs of states seeking information to support public reporting and policy purposes on a statewide basis. For example, a voluntary initiative may not be as comprehensive as a mandated reporting effort as some carriers may choose not to submit data or

may submit incomplete data, and there are no legal penalties for non-compliance. It is important to note that these private initiatives may serve as a pilot for eventual statewide APCD systems. The consensus-building process and stakeholder buy-in required for voluntary programs may prove beneficial as the APCD matures. Since the majority of state APCDs are publicly funded, this brief primarily focuses on publicly funded state initiatives.

Payers include insurance carriers, third party administrators (TPAs), pharmacy benefit managers (PBMs), dental benefit administrators, Medicaid, Children's Health Insurance Program (CHIP), Medicare, Medicare Part D, Federal Employees Health Benefits (FEHB), and TRICARE.

APCD systems collect data from the existing transaction systems in place to pay health care claims, thus leveraging data from within the insurance claims and reimbursement system. The information typically collected in an APCD includes patient demographics, provider demographics, clinical, financial, and utilization data. Because of the difficulties

associated with the collection of certain information, most states implementing APCD systems have typically excluded a number of data elements, such as denied claims, workers' compensation claims, and services provided to the uninsured.

Legislation enacted without funding

*Not a state administered system

Being Implemented
Strong Interest

GA

FL

MS

AL

Status of State-based APCD Development

Figure 1 contains a map of the states that have an existing APCD, have one under development, or have strong interest in creating one. Strong interest could range from exploration of funding models or development of legislation. Oregon and Tennessee will have live systems in 2010. In the current economic climate, states wishing to develop APCDs are finding budget challenges as it relates to initial and sustaining funding for their future APCD. (See section below on funding APCDs)

Figure 2 details the year that each state's system went live (when they began collecting data for their APCD) and also the initial year of data included in the system.

Figure 2: Timeline for State APCDs

Year in Which State's System Went Live and Furthest Year of Historical Data		
State	Year System Went Live	Furthest Year of Historical Data
Louisiana	2009	2005
Kansas	2010	2006
Massachusetts	2008	2008
Maryland	2000	1998
Maine	2003	2003
Minnesota	2010	2008
New Hampshire	2005	2005
Oregon	2010 expected	2010
Tennessee	2010 expected	2009
Utah	2009	2007
Vermont	2008	2007
Wisconsin	2008	2006
Washington	2008	2004

^{*} Shaded rows indicate non-state administered systems

Adoption Model for Populating an APCD

Prior to creating an APCD, states should develop a model for populating their APCD. This model will assist the state by laying out the framework and the order by which data will be brought into the APCD. It should be acknowledged that there is no one model for states to adopt. To date, states have successfully integrated claims from commercial payers, third-party administrators (TPAs), pharmacy benefit managers (PBMs), dental benefit administrators, Medicare Parts A-D, Medicaid, and CHIP. Figure 3 demonstrates the full range of sources of claims data that, ideally, would be in a state's APCD as the APCD evolved. This model would provide the most accurate picture of all health care services being provided to a state's residents.

The items shown in the inner-most ring of Figure 3 are data sources that, in addition to uninsured data, states desire to complete their APCDs. To date, states have not been able to implement collection of these sources due to lack of access to the

data sets. For example, a state such as Hawaii, with a large military population, has more than 100,000 individuals covered by TRICARE (representing a little less than 10 percent of the overall population). This is a significant population not currently captured.

By developing an adoption model, states can prioritize the sequence in which data sets will be added to develop the APCD. This is important as it will assist them in developing cost estimates for the APCD, as well as help determine which constituents will benefit from the APCD initially and over time. If, for instance, Medicaid feefor-service was not included initially, public program officials would be unable to use claims data to make programmatic improvements to Medicaid. Each state APCD that has been developed to date has had differences in its adoption model. Typically, commercial claims, pharmacy claims, and Medicaid claims are the first data for adoption. A well thought-out adoption model is important for shortand long-term planning efforts in the development and maintenance of a state's APCD.

Information typically collected in an APCD

- Encrypted SSN or member identification number
- Type of product (HMO, POS, Indemnity, etc.)
- Type of contract (single person, family, etc.)
- Patient demographics (DOB, gender, zip)
- Diagnosis, procedure, and NDC codes
- Information on service provider
- Prescribing physician
- Plan payments
- Member payment responsibility
- Type and date of bill paid
- Facility type
- Revenue codes
- Service dates

Data elements typically excluded in an APCD

- Services provided to uninsured (few exceptions)
- Denied claims
- Workers' compensation claims
- Premium information
- Capitation fees
- Administrative fees
- Back end settlement amounts
- Referrals
- Test results from lab work, imaging, etc.
- Provider affiliation with group practice
- Provider networks

Why Develop APCDs?

A major advantage to having an APCD is the ability to understand—in ways not otherwise possible—how and where health care dollars are being spent. This understanding of health care expenditure patterns and the performance of the health care system, via quality and access metrics, is vital to develop data-driven health reform efforts resulting in impacts (including improved access to care, reduced costs, and improved quality) that can be effectively measured.

Limitations of Current Data Sources

Current data sources are insufficient to inform and affect change in our health care delivery system.

Data Sources with Limited Service Sites: Examples of commonly used data for understanding health and health care include claims and other data from certain sub-populations (e.g., hospital discharge data and Medicare claims data) and sample-based data (e.g., the Medical Expenditure Panel Survey [MEPS] and the National Ambulatory Care Survey). Though the majority of health care in the United States is received in the outpatient setting, data and analysis for office-based care or pharmacy information at the population level are not publicly available. According to the 2005 MEPS, 71.3 percent of the U.S. population had a health care expense related to an office visit. In comparison, the percent with inpatient hospital, outpatient hospital, or emergency room expense was much lower: 7.5 percent, 15.8 percent, and 12.9 percent, respectively.³

Data Sources with Limited Populations: The Centers for Medicare & Medicaid Services (CMS) collects and makes data available based on claims paid by Medicare, including ambulatory care. This is another rich set of data, but limited. Much of the health care reform debate and policy decisions have been made based on these data, ⁴ despite the reality that the data are limited to people covered by Medicare (those 65 and older or with certain medical conditions). In addition, there can be a lengthy time delay before states and others can get access to Medicare data, making it less useful for the evaluation of ongoing reforms.

State-based Medicaid program data also provide a wealth of information about the type, quality, and cost of care for the Medicaid population. However, like Medicare data, Medicaid reflects only a small, albeit very important, portion of the population for most states. MEPS reported that, in 2007, public insurance covered only about 20 percent of the population; private insurance was the most common type of health insurance among the civilian noninstitutionalized population, with more than 60 percent of that population having private health insurance coverage.⁵ Further, 41.6 percent of medical expenses were paid by private insurance.⁶ It is within the private coverage system that payment rates vary most significantly. The impact of public program policies is often felt in the private sector and, with an APCD, it is possible to measure the impacts on the system as a whole.

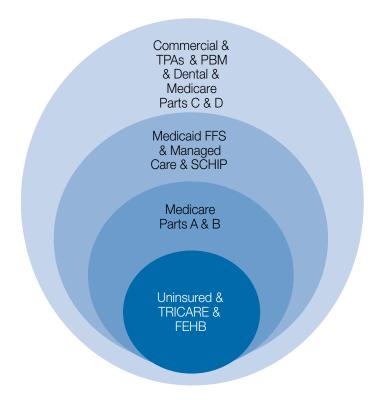
How Can APCDs Overcome These Limitations

As noted, although policymakers have good options for data in the Medicare and Medicaid populations, and for many hospital-based services, data about the experience in ambulatory care for the majority of the U.S. population who are commercially insured are not available for most states. APCDs capture data from office-based care, filling an important information gap.

Recognizing the need for more robust health care delivery data, a growing number of states are establishing, or are in the process of establishing, APCDs, which hold the potential for a much deeper understanding of patterns, quality, and cost of care across the entire population. Policy and research questions that can be answered using APCDs include:

- Which hospitals have the highest prices?
- Which health plan has the best discounts?

Figure 3: Sources of APCD Data



- What percentage of the population has had a mammogram?
- If emergency room usage by Medicaid members is higher than by the commercial population, what are the causes?
- What is the average length of time people are using antidepressant medications and what are the patient demographics?
- How far do people travel for services?
 And for which services?
- What are the utilization patterns and rates for Medicaid compared to commercial policyholders?
- What are the gaps in needed disease prevention and health promotion services?
- Which parts of a state have better access to specialists?
- Are established clinical guideline measurements related to quality, safety, and continuity of care being met?

What are the Benefits to Stakeholders?

The crux of these databases is having true transparency across the entire spectrum of health care payers. With such transparency comes access, for a wide variety of stakeholders, to information that has never before been available, thus creating the ability for actionable and accountable measures. For providers, APCDs have the potential to promote quality improvement. Payers have information to reward the delivery of high value and efficient care. And, consumers have information to make rational choices based on cost and quality information. States that have successfully created APCDs have fully engaged all stakeholders in the planning and implementation process. The stakeholders and the benefits for each group include the following:

Benefits for Policymakers

States are experiencing unprecedented fiscal crises, with most states estimating shortfalls in their 2010 budgets. Medicaid expenditures are a major cause of these shortfalls, especially as enrollment increases

as a result of growing unemployment rates. Serious decisions are being made by states including options for payment reform, provider systems accountability, and health insurance reform. APCDs can guide health care reform policies and are a relatively small investment in terms of health care expenditure.

Oregon is seeking options for payment reform, but before implementing policies, lawmakers recognized a basic need for additional information on how spending is distributed through the system. That required data that the state does not currently have. To fill this information gap, legislation to establish an APCD reporting system was passed in Oregon in 2009. Maryland's payer reporting system was linked to broader health care reform initiatives in 1993, as was Maine's in 2003.

As hospital reporting systems have demonstrated, outcomes and savings that can be measured will propel reform efforts. A recent study in the *American Journal of Medical Quality (AJMQ)* estimated that Pennsylvania's Health Care Cost Containment Council (PHC4) public reporting process prevented 1,500 deaths in one year in just six disease and treatment categories. This *AJMQ* study validates PHC4's own internal findings that improvements in hospital care during the last 12 years of public reporting have saved an estimated 49,000 lives. ^{7,8}

APCDs are a new data system, with less history than hospitalization data, but have similar potential for improving health care delivery. As more states aggregate and use all-payer databases, the knowledge base will increase along with comparative statistics to reveal variation and identify best practices in transparency, payment reform, and industry accountability at the same time as informing state and local health care policy.

Benefits for Consumers

Consumers have much to gain from APCDs. Several states have developed websites providing cost information to consumers on specific procedures for specific providers and carriers. For example, Massachusetts, Maine, and

New Hampshire have produced health cost websites that allow consumers to compare pricing of medical procedures by health care provider. The majority of states plan to add quality measures to their consumer-oriented reports and state-sponsored websites as these measures are developed. These data can be used to help patients select high-quality, low-cost providers. Benefit design changes can be made to plans to promote more rational decisions and enable consumers to become part of the cost solution. For those who are uninsured or have high-deductible plans, having access to accurate, reliable pricing information is critical. These sites provide both charge and negotiated discount information for consumers so that, depending on their benefit plan type, the information they need is available. For example, New Hampshire has developed a consumer-focused website that allows individuals to input information about the design of their health plan and be

APCD Value Proposition

Facilitating research to support state goals

• Comparative effectiveness, patient-centered medical home, payment reform.

Informing and monitoring reform

• Costs, access, quality – transparency.

Democratizing information

• Equal access to information for innovation and competition.

Reinforcing communities of interest

• Network map of shared patients for care coordination.

Population health management

• Public and private, more complete representation of population.

Better precision for pay-for-performance

• Aggregation across multiple payers for each clinician helps ensure sufficient sample size.

Supporting delivery system transformation

Episodes, global payments, system level measures.

Producing quality indicators

• Development of algorithms for measuring clinical pathways.

Based on presentation by Dwight McNeill, NAHDO/SCI APCD Conference, October 2009 provided with the cost of a procedure for different hospitals. This allows consumers to understand where they might seek the most affordable care.

Even if consumers do not directly use public cost and quality information, research has shown that consumers benefit indirectly as the providers improve quality in areas with public quality reports. Work still remains to be done to bring additional quality and preventive services information to consumers. Some employers have access to this information, but have not yet actively made it available to their employees.

Benefits for Researchers

As previously described, the majority of health care services are delivered in the primary care and outpatient settings. Data that describe this level of service delivery is lacking. Public insurance data (e.g., Medicare and Medicaid) are available for the population with this type of coverage, but these fail to capture the majority of the population. Thus, health services researchers have few options for data that support research about health care delivery in the most common setting (primary care) and for the majority of the population (those covered by commercial insurance). APCD data help to fill that void.

Examples of research uses for APCDs include a study that used methodology developed by the Agency for Healthcare Research and Quality (AHRQ) to analyze APCD data to determine the scope and costs associated with adverse drug events (ADE). The report, which focused on Maine and New Hampshire, found that more than \$30 million was spent on ADE discharges across the two states during the two-year analysis period.¹⁰

An additional study focused on the level of patient migration in New Hampshire. The study used the APCD to determine the amount of care that was delivered to a population outside of their local "capital health analysis areas" (defined as a region served by one or more hospitals). The study found that some residents were receiving care outside of their local area for up to 60-70 percent of their medical services.¹¹ This is

important for planners of health information exchange (HIE) so that they can understand the flow of patients and prioritize making electronic connections between providers in different communities.

Benefits for Providers

Though hospital quality reports are increasingly available, very little is known about physician performance and variation. APCDs are expected to help disrupt the industry's tolerance of performance blindness. Currently, some payers mine their own claims data systems for quality and utilization reports and share this information with physicians and enrolled subscribers. Because the information is limited to the insurer's network, it may not be statistically significant at the individual physician level, due to small numbers of events. CMS recognizes the need to move beyond the analysis of physician performance using Medicare data alone and is seeking options for APCDs to add power to their performance evaluations. Once physician attribution issues are resolved (i.e., how to assign patients to physicians especially in a complex treatment case with multiple providers), states with APCDs will be in a good position to look across payer systems and determine how markets and regions compare in value and efficiency.

Providers will benefit from data aggregated across the whole system to reveal a robust snapshot of care in all settings and from

all types of payers. Most states plan to develop episodes of care data to assess efficiency in both inpatient and outpatient services. Vermont and New Hampshire will use their statewide APCDs to evaluate the effectiveness of their medical home models for delivering care.

Benefits for Employers

Many of the transparency benefits for consumers also apply to employers. For those employers offering high-deductible plans or tiered networks, APCD data can assist the employees in their decisionmaking process. In addition, employer coalitions have used APCD data to benchmark cost, quality, preventive service measures, and high-cost cases across their populations. This information is used to improve health and wellness programs and to more deeply engage the employers' carriers in joint program development. Finally, to educate their employees and to engage the hospital community, two states (Maine and New Hampshire) have released hospital scorecards with cost and quality data. The cost data is derived from the APCDs. The New Hampshire Purchasers Group on Health releases this information quarterly to its employees as part of its core education programs. Moving forward, employers will do additional benchmarking against statewide metrics and continue to focus on cost reduction, quality improvement, and employee engagement.

APCDs and Quality of Care Delivery

Claims data are an excellent source of information about health care cost and utilization. They can also be used to measure the quality of care, though they have both strengths and weaknesses for use in this area. The advantage they have over clinical data is that they are available electronically and do not require time-consuming chart reviews or the requirement that providers enter clinical data into a registry. More sophisticated methodologies and algorithms are being developed that allow claims data to be aggregated into episodes of care and other bundles that gives more robust quality information. Claims data could be further enhanced if basic lab values were included in claims. It could also be blended with information in electronic medical records (EMR), although the United States' system is a long way from widespread EMR adoption. Even when EMRs are fully implemented across the health care system, the technology will need to be developed and improved to enable the data from EMRs to be integrated with claims data to allow ideal analysis of the value of care (an indicator that incorporates both the cost and quality of care).

Source: "Adding Clinical Data Elements to Administrative Data for Hospital-Level Reporting." Final Report AHRQ Contract #233-02-0088, Task Order 13, Vol. 1, July 3, 2006.

Benefits for Public Health

All-payer claims data are an important source of information for public health and community health needs assessments. APCDs provide population-based health care data for program policy and evaluation in a growing number of states. States with APCDs can now measure the rates of disease prevalence of chronic conditions and access to health care services, and make geographic comparisons to study variation in these measures. Episodes of care analyses for chronic illnesses and cancer will promote opportunities for targeted interventions and improvement. In 2007, with funding from the Centers for Disease Control and Prevention (CDC), the New Hampshire Assessment Initiative began development of chronic disease indicators based on APCD data. The claims data will be part of the state's Web-based data query system, and will supplement the information available through other administrative data sets (hospitalization, mortality, birth, and other data) about the disease profile and opportunities for public health intervention. The data are currently being used to understand Emergency Department (ED) use for people with mental illness, which will help shape community-based interventions to address the root causes of inappropriate ED use. These efforts are advancing the understanding of the utility of claims data to assess the public's health.

Benefits for Medicaid

The inclusion of Medicaid data in an APCD provides Medicaid programs with information that can be used to support policy development and inform the design of Medicaid programs. APCDs provide benchmarking for Medicaid payments compared to commercial plans and can support payment reform efforts.

The New Hampshire Medicaid program has used APCD data to support several policy efforts. APCD data were used to compare rates of ED visits for the Medicaid population compared to people covered by commercial insurance. The analysis showed higher ED utilization among Medicaid

recipients and those findings have driven efforts to reduce ED use. Another example is a report published by the New Hampshire Office of Medicaid Business and Policy that compares the use of preventive health services for the population with Medicaid coverage, compared to the commercially insured population. The findings of the study highlight opportunities for improvement in the use of preventive services (e.g., cancer screening, asthma medication) in the Medicaid population. This information has been used by the state to shape care coordination efforts.

Benefits for Commercial Payers

There are many opportunities for commercial payers as well. The benefits for commercial payers will vary depending on a state's data release rules, which will dictate how much information the payers will have access to. If, for example, payers can access provider identification number as well as competing payer identification numbers, then they can use this information in their provider contracting negotiations. In New Hampshire, payers (and providers) are using analyses of APCD data to assist in their negotiations. Again, depending upon release rules, carriers can evaluate cost, quality, and utilization rates across the entire population of a state as a way of benchmarking their performance. They can also benchmark themselves against their competitors and public programs, such as Medicaid. While there is no evidence of it yet, these databases could assist commercial payers in developing new insurance products based upon additional information gleaned from the database.

How Some Common Data Challenges Can be Addressed

States implementing APCD reporting systems will need to address important concerns, including patient privacy, payer reporting burden, data access, and identification of data users. States with APCD reporting systems have developed solutions to address those concerns, which can serve as lessons for other states.

Patient Privacy

State health data agencies and public health authorities have managed sensitive health care data and have protected the privacy and confidentiality of their data for many years. With legislative protections controlling data access and release provisions, combined with strong management controls, agencies have proven that they can balance privacy concerns with the public good that health care data provide. These agencies also recognize the importance of protecting individual privacy and respecting individual dignity to maintain the quality and integrity of health data. 13 The CDC and others have worked consistently to strengthen federal and state public health information privacy practices and legal protections.14

Various approaches states are taking in response to privacy concerns include: not collecting direct identifiers; adopting encryption methodologies; and restricting the release of information that can directly or indirectly identify an individual patient. Some states, like Minnesota, will not permit the release of detailed data outside of the authorizing agency. States can impose penalties for misuse or inappropriate disclosures. Some of these restrictions and limitations may not be ideal from a data-use perspective, but they can be used to further increase the security of the data.

Payer Reporting Burden

APCD data collection and reporting is not without costs to those who must supply the data. A key advantage of using billing data from payers is that, by leveraging the claims reimbursement transaction system, payer and provider reporting burden is reduced. Because data are generated automatically for every medical encounter in a standardized format, the use of existing data minimizes reporting costs. To the degree that states adopt a uniform reporting format, national payers will not bear the compounded costs of responding to unique state reporting requirements. States are working with the National Association of Health Data

Organizations (NAHDO), the Regional All-Payer Healthcare Information Council (RAPHIC), and America's Health Insurance Plans (AHIP) to harmonize their collection requirements to align with payer capabilities.

Data Use and Access

Most state APCD programs will make the information available in various formats for external and internal users. Though most states have a long history of reporting hospitalization data, in some states the APCD data set has posed unique challenges, largely because it includes payment information. To overcome those challenges, states aggregate and protect proprietary and other sensitive information. Ultimately, the community benefits by having access to a common source of health care systems data. States that develop a consensus plan on data uses that range from public statistics to health services and public health research will increase stakeholder support and trust. By designing data release policies that are consistent with these uses and that provide equitable access to legitimate users, the return on investment of an APCD system can be realized while providing assurance that the data are secure and privacy is maintained.

What are the General Ways of Governing and Funding an APCD?

States have adopted several approaches to governance and funding of an APCD system. This variation reflects the political environment in each state. There is no one-size-fits-all approach, and each has advantages and disadvantages. Ideally, an APCD data steward should be seen as a neutral or independent entity that is credible and trusted by all of the stakeholders. However, local environments vary and factors may preclude achieving the "ideal," so states must choose the approach that is most practical.

Governance

Generally, authority to establish a statebased APCD is developed through legislation. This allows a structure of broad legislative authority and enables states to craft the details about data collection and release through the regulatory and rulemaking process. This permits flexibility and specificity in data collection and release. In some states, an existing state agency oversees the collection and release of APCD data. The state agency often leverages its hospital reporting program infrastructure, expanding its authority and reporting regulations to encompass APCD requirements. This is the case for Massachusetts, where the APCD resides with the Division of Health Care Finance and Policy within the Office of Health and Human Services. In Tennessee, the APCD will reside under the authority of the Division of Health Planning in the Department of Finance and Administration. In both cases, the APCD is grounded in agencies tied to state health policy.

In other states, the APCD resides with an agency responsible for oversight of insurance carriers and/or licensing of carriers, as in Vermont, where the Department of Banking, Insurance, Securities, and Health Care Administration manages the APCD. In New Hampshire, it is a shared structure of governance between two state agencies. Through a memorandum of understanding, both the Department of Health and Human Services and the Department of Insurance share in the management of data collection and release, as well as production of APCD data analysis and reports.

In Maine, the authority was granted legislatively to the Maine Health Data Organization (MHDO), which is charged with the collection and analysis of claims data as well as hospital quality data for Maine residents. The MHDO was established by the Maine legislature in 1996 as an independent executive agency to collect clinical and financial health care information and to exercise responsible stewardship in making this information accessible to the public. MHDO policy is governed by a 21-member policy board

that represents health care providers, payers, and consumers.

Broad stakeholder input and a fair decision-making process is essential to building a community data system that meets the diverse needs of the users for multiple uses. Some states have established statutory commissions or advisory boards comprised of all of the major stakeholders. For example, Utah s APCD is governed by the Health Data Committee, established by the Utah Health Data Authority Act and representation is mandated for key stakeholder groups, including consumers. In Tennessee, the legislation required the establishment of the Tennessee Health Information Committee made up of state commissioners and key stakeholders to provide guidance to the Commissioner of Finance and Administration on polices relating to the establishment and management of the state APCD. A private initiative may operate under the direction of a Board of Directors such as the Puget Sound Health Alliance in Washington. Despite the structure, a key success factor to any APCD initiative will engage all of the major stakeholders, including consumers, to assure that decisions about data collection, use, and access reflect the community's needs and that solutions to technical issues are addressed.

Funding

The key to a stable statewide health data program is a stable source of ongoing funding. Like other state data systems, the start-up and maintenance costs are significant. Unlike other state data systems, such as vital statistics, APCD programs receive no direct federal funding, although some states have been able to use Medicaid federal match funding to partially support APCD development. In states that have mandated reporting, funding often comes from either general funds or mandatory fees from providers or insurers. Voluntary APCD programs are usually funded through membership fees and/or grants and contracts. All programs—mandatory and voluntary—can expect some degree of revenue from data product sales once the system is operational. In all types of programs the cost of submitting the claims

in the correct format are typically borne by whoever collects the data: the payers, insurers, or the state.

The funding for APCDs is somewhat tied to the governance structure. In Maine, the MHDO has legislative authority to equally assess fees on health care providers and payers. Revenues are derived from fees assessed on hospitals (based on net patient service revenue), carriers (based on premiums written and as reported to the Insurance Commissioner), and from TPAs (based on claims paid for plan sponsors). The fees are assessed based on relative market share. MHDO also receives a small amount of revenue (less than 5 percent of the annual revenue) from the sale of the data. Fees are placed in a dedicated account, not the general fund, and unexpended revenues carry over into the next fiscal year, with assessments adjusted downward accordingly.

Other states rely on general appropriations from the legislature. In the case of New Hampshire, the APCD is funded primarily through state budget funds for the responsible agency or department. Fees collected from releases of data, and fines collected from non-compliant carriers (those that have failed to submit data, etc.) are insignificant and account for only a small portion of funds that can be used to sustain the APCD.

Conclusion

Despite pressure to transform health care delivery and assess the value of health care services, states have realized that the information needed to support health care reform is not available. In response, states are creating APCDs to drive decisions and create transparency. Statewide APCDs are evolving and are increasingly becoming an important source of information for state policymakers, consumers, purchasers, and other stakeholders. States have demonstrated that the collection of APCD data is definitely feasible and can be quickly implemented. In the absence of legislative authority, some states are relying on private, voluntary initiatives to fill critical

information gaps. Both state agencies and private entities face an array of challenges to APCD implementation that range from funding to data release practices, with variation across states in how they are addressing these challenges. As the number of states with APCD programs increase, the payer burden to supply the data also increases. States are working to harmonize their collection requirements to align with payer capabilities. As the uses of APCD data evolve, states will share reporting methods and tools to better translate their databases into actionable information for policy and market purposes.

A Call to Action

States need access to timely and state-specific information for their policymakers and consumers to support evidence-based decisions. APCDs are unique in that they provide detailed, systemwide information to support payment reform and market and policy decisions. As more states implement APCDs, these systems have potential to support national reform efforts and comparative effectiveness research studies. Integration of APCD reporting with statelevel HIEs will leverage emerging information technology to generate clinically robust population-based data.

The question before states and the federal government is how APCDs will be authorized, funded, maintained, and utilized to support these reform efforts most efficiently and effectively. The states and the federal government should work together to explore how to leverage APCDs by integrating these systems into statewide and national information initiatives.

Credits

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Endnotes

- The Kaiser Family Foundation, statehealthfacts. org. Data Source: "Total Health Expenditures by State of Provider as a Percent of Gross State Product (GSP), 2004." National Health Expenditure Data, Health Expenditures by State, Centers for Medicare & Medicaid Services, Office of the Actuary, National Health Statistics Group. GSP from the U.S. Department of Commerce, Bureau of Economic Analysis; Accessed Feb. 11, 2010.
- 2 The Kaiser Family Foundation, statehealthfacts. org. Data Source: "Average Annual Percent Growth in Health Care Expenditures per Capita by State of Residence, 1991-2004." Health Expenditure Data, Health Expenditures by State of Residence, Centers for Medicare & Medicaid Services, Office of the Actuary, National Health Statistics Group; Accessed Feb. 11, 2010.
- 3 Agency for Healthcare Research and Quality.
 "Total Health Services-Mean and Median
 Expenses per Person with Expense and
 Distribution of Expenses by Source of Payment:
 United States, 2005." Medical Expenditure Panel
 Survey Component Data. Generated interactively.
 Dec. 3, 2008.

- 4 The Dartmouth Atlas of Health Care; available at www.dartmouthatlas.org/. Accessed Dec. 5, 2008.
- 5 Center for Financing, Access, and Cost Trends, Agency for Healthcare Research and Quality, "Medical Expenditure Panel Survey Household Component, 2007." Available at www.meps. ahrq.gov/mepsweb/data_stats/summ_tables/hc/ hlth_insr/2007/alltables.pdf. Accessed Dec. 3, 2008.
- 6 Center for Financing, Access and Cost Trends, Agency for Healthcare Research and Quality: "Medical Expenditure Panel Survey, 2005." Available at www.meps.ahrq.gov/ mepsweb/data_stats/quick_tables_search. jsp?component=1&subcomponent=0; Accessed Dec. 3, 2008.
- 7 The Patriot News, Editorial, Bill Lehr, May 2009. Available at www.pennlive.com/editorials/index. ssf/2009/05/losing_phc4_would_be_expensive. html. Accessed Feb. 21, 2010.
- 8 Hollenbeak, C. et al. "Reductions in Mortality Associated With Intensive Public Reporting of Hospital Outcomes," *American Journal of Medical* Quality, July 2008, Vol. 23, pp. 279 -86.
- 9 Hibbard, J., J. Stockard and M. Tusler. "Does Publicizing Hospital performance Stimulate Quality Improvement Efforts," *Health Affairs*, March/April 2003, Vol. 22, No. 2, pp. 84-94.
- 10 Miller, P.B. and D.S. Culver. "Issue Brief: Utilization and Costs for Adverse Drug Reactions in Maine and New Hampshire: 2005-2007," Available at www.nhhealthpolicyinstitute.unh.edu/ pdf/2009_09_03ADEIssueBrief.pdf. Accessed Jan. 6, 2010.
- 11 Miller, P.B. "Issue Brief: Care Migration of Commercially Insured Patients in New Hampshire: Building the Case for Health Information Exchange." Available at www. nhhealthpolicyinstitute.unh.edu/pdf/2008-12_NH-Patient-Migration-Analysis.pdf. Accessed Feb. 19, 2010.
- 12 New Hampshire Department of Health and Human Services. "Adult Preventive Health Care in New Hampshire Issue Brief – June 2009." Available at www.dhhs.state.nh.us/NR/rdonlyres/.