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APCD Legislation: Review of Current Practices and Critical Elements

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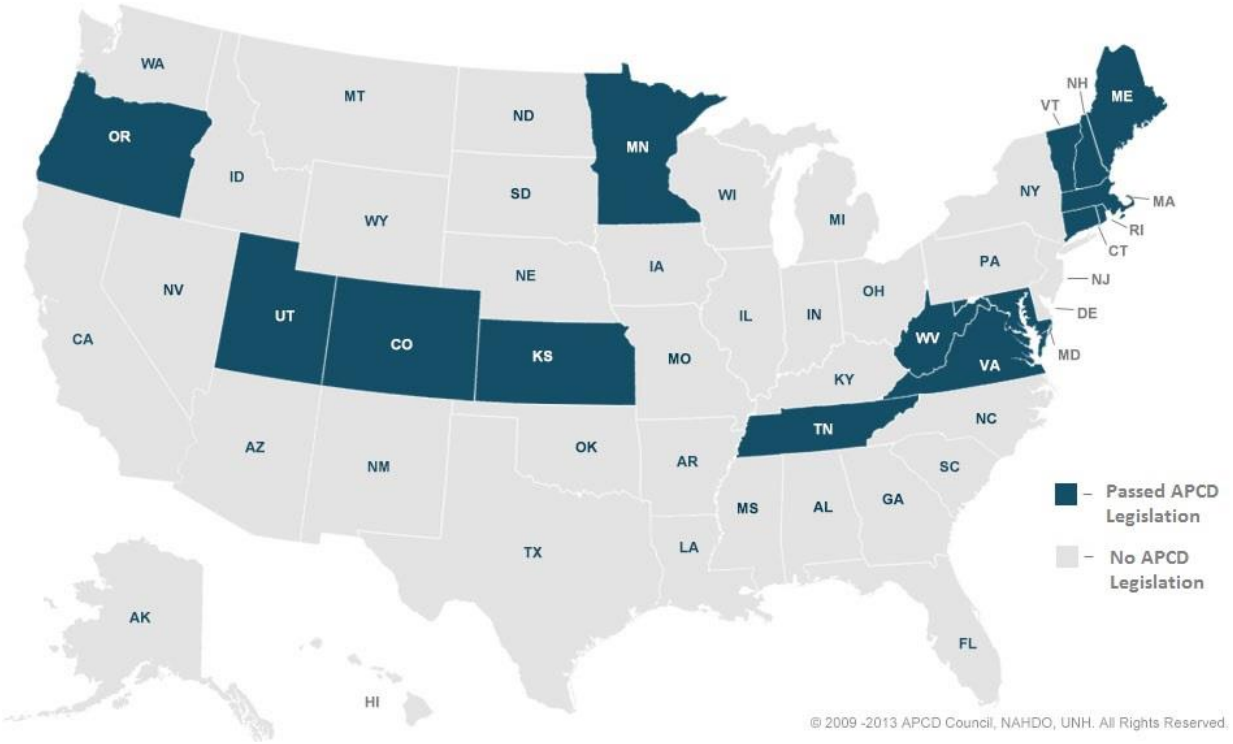
Document Purpose

This paper is intended for use by states that are considering the development of all-payer claims database (APCD) legislation, or those who are revisiting their current legislation. The goal of this paper is to provide information on the current landscape of APCD legislation while highlighting the most critical features of legislation to date.

Background

APCD legislation has existed for more than a decade, and there are currently sixteen states that have passed legislation (see Figure 1) to develop these systems. The first state to pass legislation was Maine in 2003 and the newest was Connecticut in 2012. New York managed to avoid creating new legislation entirely by modifying the existing authority for collection of hospital discharge data[i]. Connecticut has created legislation that integrates their claims data collection with their health insurance exchange (HIX). Delaware, currently considering legislation as part of a larger SIM grant effort, is working toward a model of integrating claims data with their existing, statewide clinical health information exchange (HIE).

Figure 1: States with APCD Legislation (November 2013)



To form the legal framework for an APCD, legislation is typically joined by rules or regulations for data collection and data release. The rules or regulations typically provide the more specific detail about data collection, including frequency of reporting, data elements to be captured, and file formats. This is true for several states, including Maryland and Minnesota.

The format and content of APCD legislation varies, ranging from a few paragraphs (New Hampshire) to extensive documents (Colorado). An examination of the most critical pieces of legislation is described in the next section.

Legislation Examination

Legislation for Colorado, Kansas, Massachusetts, Maryland, Maine, Minnesota, New Hampshire, Rhode Island, Tennessee, Utah, and Vermont was examined for the purposes of this paper. Six key elements in legislation are detailed below, highlighted because they are critical to any piece of APCD legislation that might be developed by additional states.

1. Purpose

Though legislation's inherent purpose is to authorize the creation of an APCD system, the purpose section of legislation delves deeper into what the state APCD will actually do. APCDs serve multiple purposes, and it is crucial for stakeholder buy-in that the purpose be clarified within the legislation. APCDs can have extremely narrow focuses and uses, such as Minnesota (limited to use by health department) or be quite broad, such as Maine (used to "improve the health of Maine citizens"). Others have evolved exponentially over time (e.g., Maryland). Clarity around purpose (e.g., utilization, cost, quality, health reform support, population health) will allow stakeholders to understand the true purpose of the APCD in the beginning, and make the role of groups, such as data release committees, easier once the APCD is live and collecting data. Declaring which stakeholders (e.g., consumers, employers, providers, 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.

Example purpose language from Maine, Utah, and New Hampshire state legislation is detailed below.

> *Maine Example*[ii]
> "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 Example[iii]
"(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)…"

New Hampshire Example[iv]
"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."

2. Governance

Governance is arguably the most important part of APCD legislation. Governance covers such items as where the APCD will reside (e.g., health department, insurance department), governance board composition, and whether there will be a designated entity for implementation. Colorado, Connecticut, and Virginia have all embarked on a designated-entity model of implementation, whereby each state has appointed a non-profit corporation. Whether this is a definitive trend or not remains to be seen, but it points to the need for states to find ways to develop innovative governance models, flexible funding, and more agile implementation structures.

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Another aspect of governance is the steering committee. Many states create steering committees that are responsible for the development of the APCD, as well as its ongoing maintenance. 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. As states develop their linkage policies (see Privacy and Confidentiality section below), these data release committees will take on larger roles.

Example governance language from Maine and Colorado state legislation is detailed below.

Maine Example[v]

"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 Example[vi]

"25.5-1-204. Advisory committee to establish an all-payer health claims database - creation - members - duties - creation of all-payer health claims database - rules - repeal. (1) (a) within forty-five business days after the effective date of this section, 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…"

3. Scope

Items typically discussed in the scope of an APCD are:

- File types to be collected (medical, pharmacy, dental, eligibility, provider, supplemental fiscal)
- 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 insurer and/or volume of business
- Schedule for data submissions
- Language around authority to enforce provisions, such as penalties for payers that do not report or misuse of the data.

Example scope language from Maryland state legislation is detailed below.

Maryland Example[vii]
"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, Ann"

4. Privacy and Confidentiality

Six critical elements found in APCD legislation:
1. *Purpose*
2. *Governance*
3. *Scope*
4. *Privacy and Confidentiality*
5. *Funding and Penalties*
6. *Reporting Requirements*

A core decision for any APCD is how to protect patient identifying information. About half of the states currently only allow de-identified patient information to be collected and released. There appears to be a recent trend toward allowing states to collect patient identifiers. These would be used for future data linkage to public health, clinical, and other datasets. 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. These policies are nascent in their development, and will require diligence and cooperation amongst stakeholders. One state, Rhode Island, has legislation[viii] allowing for a patient to opt-out of the dataset, similar to Rhode Island's clinical health information exchange (HIE); however, operationalizing policies such as this are challenging.

Example privacy and confidentiality language from Tennessee and Vermont state legislation is detailed below.

Tennessee Example[ix]
"(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 Example[x]
"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."

5. Funding and Penalties

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. Another concept that states often address in their legislative efforts is penalties for non-compliance by data submitters. These are designed to ensure that all submitters are sending in their data regularly, to promote the integrity of the overall database and to maintain cost equity among the submitters.

Example funding and penalties language from Kansas state legislation is detailed below.

Kansas Example[xi]
"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 therto;
(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…"

6. Reporting Requirements

As states look to develop accountability structures, one option is to define annual or milestone-based reporting requirements. These may be typified as an annual report to the Governor's office, the Legislature, or a legislative committee. They may also be milestone-based such as when funding is raised or systems are implemented.

Example reporting requirement language from Colorado and New York state legislation is detailed below.

Colorado Example[xii]
"(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"

New York Example[xiii]
"9. The commissioner shall publish an annual report relating to health care utilization, cost, quality, and safety, including data on health disparities."

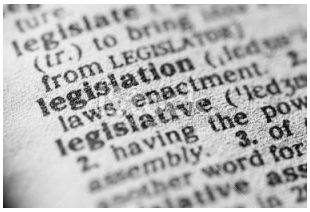
It is important to note that each state APCD is unique, and will likely require elements beyond what is described above. As previously mentioned, the legislation is often a broad overview of the intent and governance of the APCD, with detail about the system captured in rules or regulations. In general, states need to determine what level of detail should be included in legislation and what level of detail should be handled through rules or regulations. These decisions are state-specific, reflecting the legislative process in each state. Some of the unique items found in other states' detail APCD data collection include:

- Definitions (Colorado, Maryland, New Hampshire)
- Interagency agreements (Colorado, Virginia)
- Encryption (Maryland, New Hampshire)
- Schedule for mandatory data reporting (Colorado, Maryland, Minnesota, Tennessee, Vermont, Virginia)
- A review, validation, and comment period for public performance reports

Example language from New York **legislation** details what will be specified in **regulations** is below.

New York Example[xiv]
"2. Regulations governing the statewide planning and research cooperative system shall include, but not be limited to, the following: (a) Specification of patient and other data elements and format to be reported including data related to:
(i) inpatient hospitalization data from general hospitals;
(ii) ambulatory surgery data from hospital-based ambulatory surgery services and all other ambulatory surgery facilities licensed under this article;
(iii) emergency department data from general hospitals;
(iv) outpatient clinic data from general hospitals and diagnostic and treatment centers licensed under this article, provided, however, that notwithstanding subdivision one of this section the commissioner, in consultation with the health care industry, is authorized to promulgate or adopt any rules or regulations necessary to implement the collection of data pursuant to this subparagraph; and
(v) the data specified in this paragraph shall include the identification of patients transferred, admitted or treated subsequent to a medical, surgical or diagnostic procedure by a licensed health care professional at a site or facility other than those specified in subparagraph (i), (ii), (iii) or (iv) of this paragraph.
(b) Standards to assure the protection of patient privacy in data collected and released under this section.
(c) Standards for the publication and release of data reported in accordance with this section"

Conclusions



This document highlights the critical features of APCD legislation. It aims to inform states that are contemplating the development or modification of APCD legislation that they do not need to reinvent the wheel. Framing legislation with the six critical elements described above, while exploring the additional needs of the state with stakeholders, will provide a framework for successful APCD legislation.

For direct links to state legislation, or for additional information beyond the scope of this paper, please visit the APCD Council website (www.apcdcouncil.org).

About the Authors

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[i] http://public.leginfo.state.ny.us/LAWSSEAF.cgi?QUERYTYPE=LAWS+&QUERYDATA=$$PBH2816$$@TXPBH02816+&LIST=LAW+&BROWSER=EXPLORER+&TOKEN=32923920+&TARGET=VIEW

[ii] http://www.mainelegislature.org/legis/statutes/22/title22sec8703.html

[iii] http://le.utah.gov/~2007/bills/hbillenr/hb0009.pdf

[iv] http://www.gencourt.state.nh.us/rsa/html/XXXVII/420-G/420-G-11-a.htm

[v] http://www.mainelegislature.org/legis/statutes/22/title22sec8703.html

[vi] http://www.leg.state.co.us/CLICS/CLICS2010A/csl.nsf/fsbillcont3/7772EFE1E998E627872576B700617FA4?Open&file=1330_enr.pdf

[vii] http://www.dsd.state.md.us/comar/SubtitleSearch.aspx?search=10.25.06.*

[viii] http://webserver.rilin.state.ri.us/Statutes/TITLE23/23-17.17/23-17.17-9.HTM

[ix] http://state.tn.us/sos/acts/106/pub/pc0611.pdf

[x] http://www.leg.state.vt.us/statutes/fullsection.cfm?Title=18&Chapter=221&Section=09410

[xi] http://kansasstatutes.lesterama.org/Chapter_65/Article_68/

[xii] http://www.leg.state.co.us/CLICS/CLICS2010A/csl.nsf/fsbillcont3/7772EFE1E998E627872576B700617FA4?Open&file=1330_enr.pdf

[xiii] http://public.leginfo.state.ny.us/LAWSSEAF.cgi?QUERYTYPE=LAWS+&QUERYDATA=$$PBH2816$$@TXPBH02816+&LIST=LAW+&BROWSER=EXPLORER+&TOKEN=32923920+&TARGET=VIEW

[xiv] http://public.leginfo.state.ny.us/LAWSSEAF.cgi?QUERYTYPE=LAWS+&QUERYDATA=$$PBH2816$$@TXPBH02816+&LIST=LAW+&BROWSER=EXPLORER+&TOKEN=32923920+&TARGET=VIEW