

Emergence, convergence, and differentiation of organizational forms of health data governance: The U.S. All Payer Claims Databases (APCD) movement

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Abstract

In this research we are investigating how different organizational forms of data governance develop in response to the opportunities and challenges to aggregate, curate, and utilize digital health data for health systems improvement and market regulation. We are examining (i) how/when do governance arrangements coalesce around specific domains of health data resources as identifiable organizational forms; (ii) what influences how (or whether) these forms develop in a health care market, and (iii) what factors contribute to convergence or divergence in organizational forms across markets? To address these questions, we are conducting an in-depth, multi-level field study of the movement to establish all payer claims database (APCD) organizations in the U.S. healthcare sector. Among states with an APCD there is substantial variety in the data domains, stakeholders, governance goals and structures of the organization, indicating local variation and divergence, as well interstate and national initiatives to encourage convergence along some dimensions. This provides a rich opportunity to study institutional and market factors that contribute to (or inhibit) emergence, convergence, or divergence of health data governance forms and the implications for health care sector management and improvement that may result. In this paper we report preliminary findings and analysis of this study.

1. Introduction and motivation

In recent years, governments, healthcare provider organizations, insurers, IT vendors and many other healthcare industry actors have dramatically increased spending on health information technologies (HIT). The widespread expectation is that improved collection, utilization, and sharing of health data are essential to address rising costs, quality and safety issues, and opportunities for innovation and coordination in health services delivery (Institute of Medicine, 1999, 2001; National Institutes of Health, 2019; Tang et al., 2006). For instance, in the

U.S., the Health Information Technology for Economic and Clinical Health (HITECH) legislation committed over \$20 billion to stimulate HIT adoption (Blumenthal, 2010) in the 2010s, and the health IT market is now expected to reach \$280 billion by 2021. Through these HIT investments, digitization of health data has generated vast stockpiles of highly coveted clinical and transactional health data.

These data resources could be used to address pressing societal concerns, such as health care operational and system-level improvement, and innovations such as personalized medicine. Care coordination and efficient service delivery increasingly depend on these electronic health data stores (Bates, 2015; Rudin & Bates 2013; Singh, Baird, & Mathiassen, 2018), particularly with the transition to newer service delivery forms such as Accountable Care Organizations (ACOs) and Patient Centered Medical Homes (PCMH) (National Institutes of Health, 2019; Richardson et al., 2015; Wu, Rundall, Shortell, & Bloom, 2016). Beyond their critical role in facilitating health service delivery, health data resources are essential for policy makers and regulators tasked with understanding, analyzing and then regulating health systems markets to address societal needs and limitations (Ericson & Starc, 2015; McPake and Hanson, 2016; Wang, Kung, & Byrd, 2018). Effectively using digital health data stores is particularly important as regulators and third-party payers (governments, health insurers) advance the shift from fee-for-service reimbursements to value-based care models (Colla, Lewis, Bergquist, & Shortell, 2016; McWilliams, 2016).

To activate these beneficial uses requires that health care data be widely shared and broadly utilized among health sector organizations. However, despite high expectations for societal and economic value that could be realized from digitized health data and long-term advocacy by healthcare and government leaders, effective health data governance remains an

elusive goal (Diamond et al., 2009; Elliott et al., 2013; Hripesak et al., 2014; Kanaan & Carr, 2009; Rodwin, 2009; Rosenbaum, 2010; Ross et al., 2014). The degree of health data interoperability and exchange needed to achieve these societal goals is problematic for many reasons. In the U.S. and elsewhere, the healthcare sector is complex in terms of government regulation, health industry actors, professional practices and inter-organizational relationships (Scott et al., 2000). Digitized health data are created in myriad incompatible systems spread across collaborative and competing organizations, including hospitals, physician practices, nursing homes, third-party payers (insurers, State and Federal governments), pharmacies, testing laboratories, and increasingly, by IT vendors that provide HIT systems. This complexity contributes to technical barriers to data exchange such as limited interoperability of HIT systems and data encoding standards. It also encourages but also hinders effective deployment of HIT systems (Davidson & Chismar, 2007; Oborn et al., 2011). Legal and policy regulations for patient privacy (i.e., the Health Insurance Portability and Privacy Act (HIPAA)) limit the degree to which some health data (personally identifiable health data) can be exchanged or sold (Office of the National Coordinator for Health Information Technology, 2015; Tanner, 2016), as well as the accumulation of health data repositories for research and regulatory purposes (Lane & Schur, 2010; Hripesak et al., 2014; Rosenbaum, 2010).

The proprietary claims that organizations stake on health data generated or maintained by their own HIT systems also limit widespread data sharing. Some health care data are necessarily shared (to a limited extent) for delivering healthcare services to patients and for adjudicating payments for services (e.g., billings claims data). However, for organizations, health data are critical resources to enhance market share, competitive position, and operational efficiency. Sharing these resources with competitors or within a provider/buyer relationship (e.g., with third-

party payers) could weaken the organization's ability to profit from its data or expose it to loss, liability or unwanted scrutiny of business practices. As a result, struggles over health data access for patient care, for system-wide improvements, and for research have persisted for decades (Hripcsak et al., 2014; Rosenbaum, 2010). Governing authorities have applied substantial guidance, stimulus, and regulation to accelerate health data digitization and sharing yet the outcomes of these efforts have been mixed (Devine, 2017; Eden, 2016; Langabeer & Champagne, 2015; Rahrkar et al., 2015).

In the research project reported here, we are investigating how different organizational forms of data governance develop in response to the opportunities and challenges to aggregate, curate, and utilize digital health data for health systems improvement and market regulation. In earlier research, we characterized generic forms of health data governance in terms of data domains, stakeholders, value propositions, and governance goals and structures (blinded reference). In the research project reported here, we are investigating (i) how/when do governance arrangements coalesce around specific domains of health data resources as identifiable organizational forms; (ii) what influences how (or whether) these forms develop in a health care institutional field, and (iii) what factors contribute to convergence or divergence in organizational forms across these fields?

To address these questions, we are conducting an in-depth field study of the movement to establish all payer claims database (APCD) organizations in the U.S. healthcare sector. Legislatively-mandated APCD organizations at the state level have developed in twenty U.S. states, an additional six states have APCDs run by voluntary submission, ten are in the process of building an APCD, while the remainder have declined to pursue or tried and then failed to establish an APCD organization. Among states with an APCD there is substantial variety in the

data domains, stakeholders, governance goals and structures of the organization, indicating local variation and divergence. There are also interstate and national initiatives to encourage convergence along some dimensions. Thus, the APCD case provides a rich opportunity to study what institutional and market factors contribute to (or inhibit) emergence, convergence, or divergence of health data governance forms and the implications for health care sector management and improvement that may result.

In the following sections, we review the theoretical foundations in the study of organizational forms and in data governance, describe the case study setting, and outline the overall study approach. We then present preliminary findings on key factors that have contributed to the developments of the APCD movement over the past 15 years and the variations in the APCD organization form of health insurance claims data. We discuss the implications of these factors for whether and how health data governance forms, oriented toward health systems improvement, may develop and conclude with our plans for extending this research project empirically and theoretically.

2.0 Theoretical foundations and related literature

2.1 The study of organizational forms

Organizational forms are identified by prototypical arrangements of core properties including goals, authority relations, technologies, and served markets (Scott, 2001) characteristic of one or more organizations. Organizational theorists have studied why and how different forms develop, because the diversity of organizational forms provides a repository of social, economic, and technical solutions to social needs (Hannan & Freeman, 1989; Ruef, 2000). Forms take shape in response to endogenous and exogenous (environmental, technological, regulatory) change (Rao et al., 2000; Ruef, 2000; Scott, 2001). Distinctive forms arise within a field comprised of

interrelated populations, or sets of organizations that produce similar products and services, and actors such as government regulators or industry associations (DiMaggio & Powell, 1991). Over time, organizations in a field tend to become more similar in form, due to similar competitive pressures (Hannan & Freeman, 1977) and institutional norms and expectations (DiMaggio & Powell, 1991). However, new forms may emerge and existing forms evolve as a result of changes in interrelationships among actors, cultural expectations and typifications of the community, and social demands of vocal and well-positioned community participants (Ruef, 2000). Within highly institutionalized fields, regulatory change often engenders new forms, whereas in technological fields, technology developments can lead to novel forms (Navis & Glynn, 2010). Well-positioned actors and social movements can advocate for and then help legitimate new forms (Rao et al., 2000; Ruef, 2000).

The convergence of these multiple influences was documented by Scott et al.'s (2000) study of how new rules, governance mechanism, logics and actors contributed to turbulent change in the healthcare field and the emergence of new organizational forms such as multi-hospital systems and health maintenance organizations. Whether new forms will develop in a field can be explained in part by the “identity space” available for a new form to address unmet needs and demands through distinctive organizational arrangements (Ruef, 2000). However, a new form must be distinguished from existing forms, in terms of its ability to address these needs, in order to become recognized and legitimated in the field (Gioia et al., 2010). Ruef (2000) argues that the identity of potential (or emerging) organizational forms will be evident in the discourses of influential community participants in debates about and discussions of procedures, values, and other symbols of importance to the community. Rao et al. (2000) reinforce the importance of identity and discourse by arguing that new organizational forms

develop through political projects of social movements or institutional entrepreneurs to de-institutionalize norms and values of current forms, establish new forms embodying new values, and mobilize constituencies to support new forms.

In this research we are applying the concept of organizational form to investigate how health data governance arrangements take form. Our particular interests are in health data stores that develop or are managed across organizational boundaries and that are used for health system improvement, design, and regulation. Thus, we are examining how the varied goals for health care system management and regulation, the authority relations among health sector actors and the health data stores they generate or manage, health information technologies that generate and are used to manage / mine health data stores, and intended markets for health data analytics (individual and organizational users of health data) may take shape and develop within and across institutional fields. We include in our examination of institutional fields health care providers, third party insurers, state and Federal regulators and policy makers, health data aggregators / stewards, collective actors such as professional association, and so on.

2.2 Data governance within and across organizational boundaries

Data governance generally refers to management of an organization's data and is viewed as the responsibility of the organization that generates the data through IT systems (Data Governance Institute, nd: 2). Enterprise data are increasingly viewed as a strategic asset requiring effective governance so that the organization can realize its potential business value and be protected from loss (Khatri & Brown, 2010; Otto, 2011; Tallon et al., 2013; Weill & Ross, 2004). A plethora of practitioner literature specifies and advocates data governance practices within organizations, such as steering committees or policy setting boards to formulate policies, standards, accountabilities, and enforcement methods (Weill & Ross, 2004). Much of this

literature details technical solutions such as building data warehouses (cf. Inmon, 1996; Kimball & Ross, 2013) or data stewardship roles and responsibilities (Baker & Yarmey, 2009), such as standardizing data definitions, improving data quality, maintaining data integrity, aggregating and warehousing data in secure technological facilities, and granting access only to authorized data users (cf. Data Governance Institute, n.d.; Ladley, 2012; Plotkin, 2013; Sarsfield, 2009).

In this era of ubiquitous computing devices that capture so many human activities as digital data, societal opportunities and concerns about how these data will be utilized are widely debated, and new forms of data governance are appearing. The “open data” movement has highlighted opportunities for innovation through sharing publicly held data archives with private sector organizations (Jetzek et al., 2014). Public-private or university-firm partnerships are also developing that make privately held data more accessible to address societal challenges and innovation in fields such as genetics research, clinical trials, and climate science (Perkmann & Schildt, 2015; Sussha, Janssen, & Verhulst, 2017). However, little research has yet addressed these or other organizational forms of big data governance and their possible societal consequences. We argue here that research is needed to better understand how stakeholders’ values and interests guide governance and stewardship policies, structures, and goals and thus what types of value will or could be realized from big data resources. Addressing these issues is particularly important in the health care sector, where promising opportunities for societal improvements are juxtaposed with potential threats to individual privacy, autonomy, and access to health care services (blinded reference).

2.3 Challenges and opportunities of health data governance

Recent health IT investments are exponentially increasing digital health data resources and their value to multiple stakeholders. The mix of private/public and for profit/not-for-profit organizations highlight tensions in these multiple stakeholders’ values and interests in data

governance (Devine, 2017; Eden, 2016; Langabeer & Champagne, 2015; Raturkar et al., 2015). Healthcare is not a pure market, as government regulation always has some role, and health providers are expected to manage and improve services. To do this, regulators and health systems managers require data (Bates, 2015; Rudin & Bates 2013). There are various sources of data that can be gleaned from transactional processes (e.g., claims), care processes (e.g., clinical EHRs), and regulatory requirements (e.g., specific reporting). However, these data are often incomplete or erroneous, lack federation, or are otherwise difficult to exploit.

There are robust discussions on health data governance and stewardship among multiple stakeholders, novel forms of data governance in the public and private sector have emerged or are emerging, and current and recent developments provide evidence regarding efficacy and outcomes for various forms (Diamond et al., 2009; Elliott et al., 2013; Hripcsak et al., 2014; Rosenbaum, 2010; Ross et al., 2014). Among the most vocal advocates for making health data more widely available are clinical and health economics researchers. However, knowledge exchange on how to address regulations with proper health data stewardship is limited (Holmes et al., 2014), though some case reports describe particular data governance organizations (cf. Gardner et al., 2012; McMurry et al., 2013). For instance, data enclaves combine statistical, technical, legal, and operational controls with researcher training in order to satisfy privacy rule requirements and expedite researchers' access to data (Lane & Schur, 2010). Distributed research networks (DRNs) comprised of partnering institutions target specific research domains and a network of researchers; data governance then reflects regulations and policies established at institution, network, and federal levels (Holmes et al., 2014).

Despite limitations, these growing health data resources are valuable, not only to healthcare industry players but also to third parties who seek to monetize health data (e.g.,

pharmaceutical companies) (Wang, Kung, & Byrd, 2018). How are the needs of various stakeholders met, and what organizational forms will emerge to govern these data? We argue that growing stockpiles of digitalized health data represent critical, shared societal resources. Governance of shared resources may be carried out by an external authority or through self-regulation mechanisms, which may take the form of policy-making networks, hierarchies, market-based competition, or negotiation (Jansen, 2007). New forms are likely to arise when authority is fragmented and multiple governance models co-exist, including a mix of public-private sector actors (coregulation), hierarchical and non-hierarchical steering, and participation of private actors and the public in deliberations (multi-stakeholder regulation) (Haufler, 2003; Kronsell & Bäckstrand, 2010). These approaches to shared environmental resources are applicable to the generation and management of digitalized health data stockpiles, which are accumulating across organizational settings and have implications for the welfare of multiple types of health care sector actors (consumers, health care providers, regulators, third party payers, etc.). Thus, health data governance and related organizational forms present important avenues for inquiry. We thus are investigating the following focused research questions.

2.4 Research Questions

RQ1. *What organizational forms are emerging to address challenges and opportunities of data governance in the U.S. healthcare field, as digitalized personal health data become increasingly abundant?* Recent promising developments suggest that healthcare is ripe for the development of new organizational forms of data governance to facilitate value realization while balancing stakeholder interests and needs. This presents an opportunity to advance knowledge of how organizational forms take shape and emerge that will address growing societal and organizational requirements for data governance.

RQ2. *What institutional and sociotechnical factors enable or inhibit the establishment of new organizational forms of health data governance within the U.S. healthcare field?* Despite the potential for large-scale health data resources to create social and economic value, effective data governance remains an elusive goal. Researchers and practitioners have worked for many years to reduce technical barriers to data interoperability. Yet legal, competitive, and economic barriers may pose even more persistent roadblocks. Understanding whether and how new organizational forms can develop as stewards of digitalized health data resources, despite well-known and as yet unrecognized constraints, is vital to regulators, industry actors, and innovators who may see opportunities to deliver the potential value.

RQ3. *How do various organizational forms of data governance address the multiple, possibly conflicting interests and values of societal and organizational stakeholders, and what then are the outcomes for societal, organizational, and individual stakeholders?* Health data represent valuable resources that may be well-or poorly-managed in terms of the societal outcomes. As research into environmental resource management has demonstrated, traditional governance approaches that depend on hierarchical forms and administrative logics are insufficient to address the complexity of technically advanced, multi-stakeholder resources (Haufler, 2003; Moore & Hartley, 2008). Thus, advancing our knowledge of how varied structures for data governance may be more or less effective at producing desired outcomes is important to inform innovators, managers, and policymakers on how to best design or endorse new forms.

3. Research design and methods

To address these questions, we are undertaking a multi-level, multi-year research project to examine the emergence and development of a novel form, the All-Payer Claims Databases (APCDs) movement in the U.S.

3.1 Case setting: The APCD movement in the U.S.

APCDs are data governance organizations that aggregate and govern health data, primarily medical claims collected from private and public payers along with some clinical data. APCD data are typically reported by third party payers (health insurers) to states¹, usually as part of a state mandate. The data domains aggregated by APCDs have significant advantages for addressing health data analysis requirements for policy makers, researchers and consumers for health service price, resource use, and service quality information across care sites, rather than data sources limited to hospitalizations and emergency department visits reported as part of discharge data systems maintained by state governments or hospital associations. APCD data resources potentially include large sample sizes, geographic representation, and longitudinal information on a wide range of individual patients and their use of health care services in outpatient and hospital settings (Agency for Healthcare Research and Quality, 2017). A limitation of APCD data domains is their focus on insurance claims data, and thus on insured individuals; other data sources are required to assess activity among uninsured patients (for instance, hospital discharge datasets).

These data represent important resources for insurers, health care providers, government agencies, researchers, policymakers, as well as individual consumers. In countries with a single-payer system, such as Taiwan, such data are collected daily and used to monitor and to improve health service delivery. Compiling this type of data is difficult in the U.S., with its mixed public-

¹ Data are reported directly to states when the APCD is legislatively mandated and the APCD is housed in a state government agency. If the APCD is managed by a third-party, then the reporting is not directly to the state.

private payer system that includes Centers for Medicare and Medicaid, 50 state Medicaid programs, and over 800 national, regional, and local private insurers with a multitude of programs customized to marketplaces. Nonetheless, recognizing the opportunities for utilizing claims data to address escalating health care system costs and management of some clinical services, legislatively-mandated APCD organizations at the state level have developed in twenty U.S. states, an additional six states have APCDs run by voluntary submission, and ten are in the process of building an APCD. Each state desiring to create an APCD has developed legislation to build an APCD organization, and a national organization exists to facilitate development of APCDs (APCD Council, 2018).

Development of APCDs has been problematic, due in part to technical challenges as well as to conflicting stakeholder interests and competing organizational forms for health data analysis (including organizations' self-reporting of summary statistics). For instance, the United States Supreme Court case *Gobeille v. Liberty Mutual Insurance Company* (2016) successfully challenged a state's authority to require submission of all claims data from private insurers². General data governance policies and structures have been customized to local circumstances, and, as a result, the APCD organizations are developing with great variation in the goals, authority relationships, technologies and markets for health data served (i.e., organizational forms). Thus, the APCDs provide an ideal context to address our study's objectives. To date 33 U.S. states are in different stages of initiating, implementing or operating their state APCDs, Contestation among varied stakeholders nationally as well as within states, as well as regulatory and technical challenges, have influenced how individual APCD organizations have taken shape and progressed. This process of emergence, with both convergence and differentiation in form,

² In particular, Employee Retirement Income Security Act (*ERISA*) plans provided by employers are currently exempted from APCD reporting, due to the added burdens of providing data. Implementation of this exemption has varied across states, however.

provides evidence of variation in organizational forms, governance structures, and governance goals and the efficacy and outcomes of various forms.

3.2 Research study design

We are conducting a series of embedded case studies (Yin, 1994) of APCDs in the U.S, focusing on a national-level case, four state-level cases, and an in-depth field-level case under development (State of Hawai‘i). Case studies include examining the history and development of the APCDs within and across states, the roles and actions of actors within states and at the national level, such as the Center for Medicare and Medicaid services (CMS), state departments of insurance and Medicaid organizations, state legislatures, health provider networks, insurers, collective actors such as vendors, consultants, and professional associations, and complementary and competing health data governance forms. This design models the general approach Ruef (2000) outlined to study emergence of organizational forms: (i) examine the context of inter-relationships between various sector actors in the organizational field; (ii) examine the constitutive rules that delineate the identities and typifications of forms in a community or field; (iii) consider the distribution of types (population) of organizational forms that compete for resources and legitimacy and thus affect emergence; and (iv) highlight the social demands for new forms, particularly from vocal and well-positioned community participants.

Data collection includes interviews with participants in these various organizations and in APCD organizations, document review, and attendance at national conferences in which APCD activities are presented/discussed. We have built a corpus of over 700 documents relevant to APCD history and development. This includes state and federal legislation and guidelines, court documents, reports and memos to and from legislators, white papers prepared by data vendors, case studies and reports prepared by APCDs, APCD committee and board minutes, newspaper

articles, conference proceedings, scholarly publications, presentations, and technical manuals prepared by data vendors, APCDs, and supporting agencies. The APCD Council (<https://www.apcdouncil.org/>) has developed and maintains archives of documents and links to state agencies, which points to or document much of the APCD history and current activity.

Here, we report on preliminary findings of the national level case study, focusing on the factors influencing the APCD movement overall and highlighting areas for further research.

4. Preliminary Findings

4.1 Background of the APCD movement in the U.S.

The emergence of APCDs can best be understood in the context of changes in the health insurance marketplace in the U.S. over the past several decades. Figure 1 highlights some key milestones in this process. With growing healthcare costs, and the increasing complexity and importance of the health insurance marketplace, Medicare and Medicaid expansion, and federal legislation prompting health delivery and payment reform, many stakeholders – and in particular state governments themselves – have sought information about healthcare cost, utilization, and equity. In the U.S., the states are responsible for regulating all insurance markets. Typically a Department of Insurance regulates insurers by licensing insurers and assuring that insurers maintain adequate financial reserves to cover claims. In some states, Departments of Insurance also review, approve, or regulate insurance rates and provisions. As private and for-profit health insurance markets have grown in size and complexity, some U.S. states have taken on increased regulatory oversight, to assess drivers of health cost growth, quality, and access to health care services. The state's need for health care data, and particularly insurance claims data to assess costs and utilization across settings and populations, to set policy and conduct regulatory oversight, has contributed to the interest in and growth of APCDs.

APCDs first were developed in the Northeast U.S., with the State of Maine establishing the first in 2003. Figure 2, adapted from the APCD Council website and expand with our data analysis, highlights the range of U.S. states with an APCD in place or underway and the timing of their establishment. The movement to disseminate ideas about APCDs, and promote sharing of legislation templates, experiences, and activities, was fostered by the National Association of Health Data Organizations (NAHDO) and later by the APCD Council. The latter began to take form in 2007, when the Regional All-Payer HealthCare Information Council (RAPHIC) began supporting APCD development for other northeastern states. That charge expanded in 2010 when RAPHIC became the APCD Council and began more intentional national outreach. This latter development reflects the impact of the Affordable Care Act (ACA). This federal legislation provides a strong stimulus for states to move forward with APCDs as a means to evaluate the costs and effectiveness of health care insurance markets in the state and to assess health care costs overall.

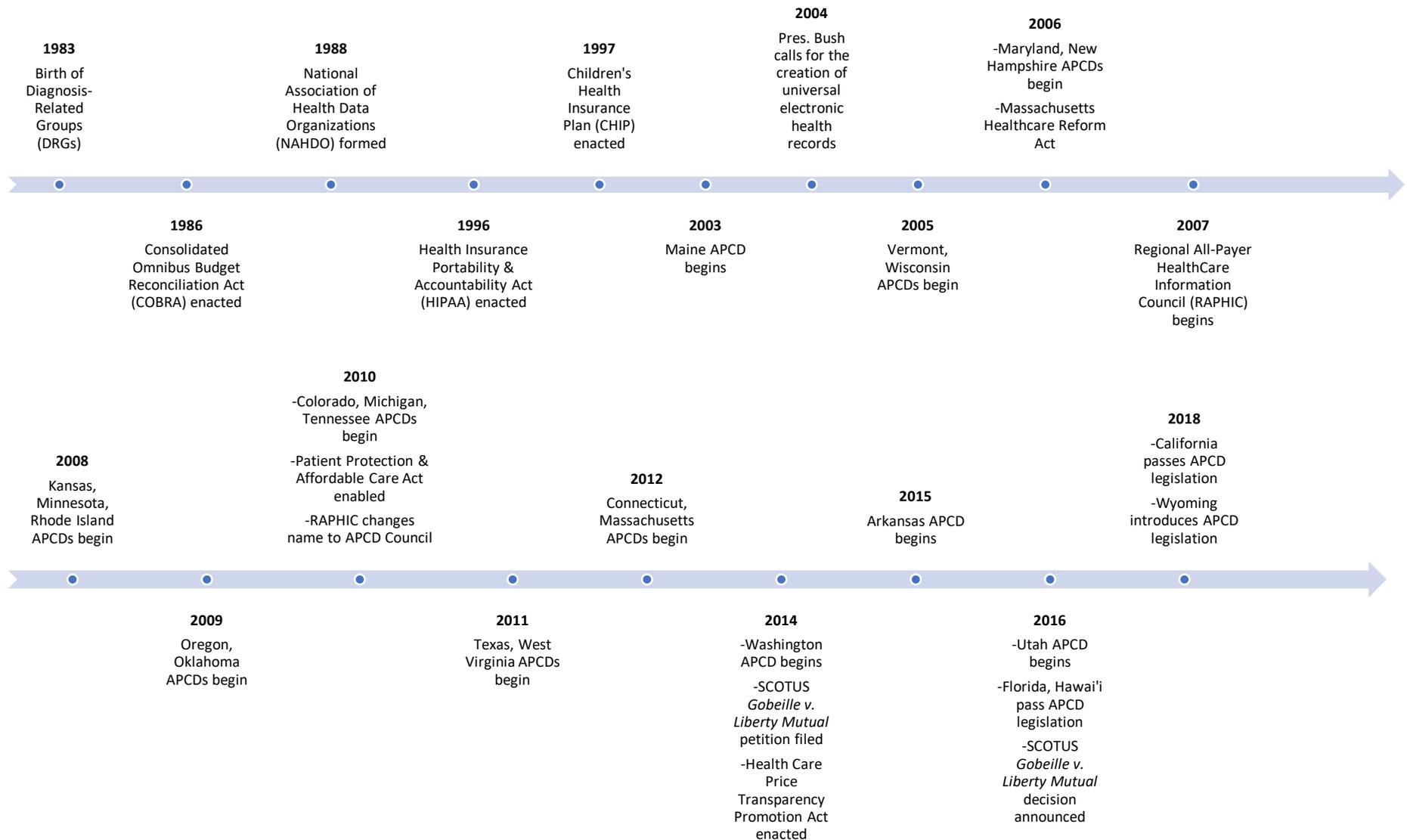
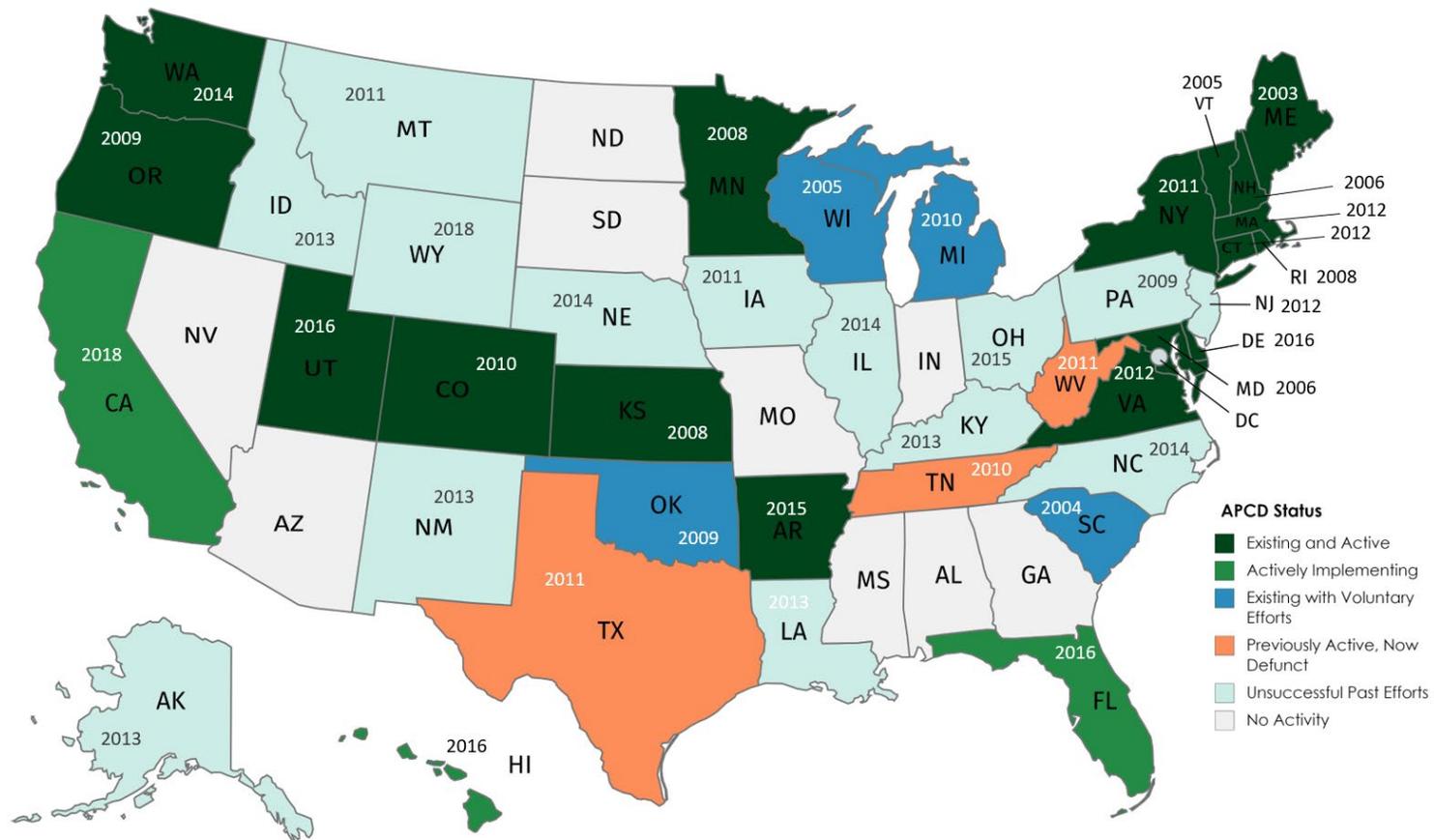


Figure 1. Timeline of key moments in the APCD movement in the U.S.



Created with mapchart.net ©

Figure 2. Map of state-level APCD status in the U.S.³

³ Adapted from APCDcouncil.org archives.

4.2 Factors influencing the emergence, convergence, and divergence of APCDs

In interviews and observations of participants in the APCD movement, we have heard the phrase, “when you’ve seen one APCD, you’ve seen one APCD” expressed repeatedly. This catchphrase reflects the variation within the APCD organizational form and some contestation over what type of health data governance organization qualifies for the term APCD. Our preliminary analysis highlights state health care market conditions and state legislative mandates as key influences on whether or not an APCD takes form in a state and that contribute to the differentiation in the organizational form across states, that is, differences in the data domains governed, authoritative relationships and organizational arrangements, technologies employed, and markets served by the APCD. At the same time, there are similarities in these individual instances of APCDs that allow the discourse, plans, and activities of APCD organizations to maintain coherence and focus. Promotion of APCD initiatives by collective actors and collaborative interstate agreements contribute to convergence of the form, for instance, through cooperative standardization of data submission guidelines. Preliminary findings suggest how these factors contribute to these oppositional trends of convergence and differentiation in form.

4.2.2 *Differentiating APCD: State health care market and legislative mandates*

Most APCDs result from state legislation, and are further administered by a state agency, such as a state’s Department of Insurance or Department of Health (see Table 1). Michigan and South Carolina, whose APCDs are run by voluntary efforts, are the only states with APCDs where there was no state legislative activity preceding the establishment of an APCD. The founding legislation represents a compromise among various stakeholders in the local market place regarding what data can or should be gathered, what types of entities should act as stewards for and govern the data, and what data uses and distributions are permissible. Most

APCDs have been established as an organization within another state agency, such as the Department of Health or the Department of Insurance, with various authoritative relationships between the APCD and various agencies. Several have been established as not-for-profit entities operating outside of the state government. For example, in Colorado, the APCD was established as an independent, not-for profit whereas in Hawai'i, legislation allocated the stewardship role to a University of Hawai'i entity. In the latter case, this decision reflected the requirement for grant funding that the entity not be an “interested party,” that is an insurer or provider organization.

Legislatively Mandated Efforts			Voluntary Efforts
Directly Administered by State Agency	Run by Non-Profit, Non-State Agency	Administered by Data Vendor	
2003 Maine 2005 Vermont 2006 Maryland 2008 Kansas, Minnesota, Rhode Island 2009 Oregon 2011 New York 2012 Connecticut, Massachusetts, Virginia* 2016 Delaware, Florida, Utah 2018 California	2010 Colorado 2014 Washington 2015 Arkansas 2016 Hawai'i	2006 New Hampshire	2004 South Carolina 2005 Wisconsin 2009 Oklahoma 2010 Michigan
*Virginia has a legislatively-mandated APCD with voluntary claims submission.			

Table 1. Administration of active APCDs in the U.S.

Market concentration and the differential power between health care sector actors play a role in how the APCD legislation takes form and is implemented. Interestingly, some states, which are typically given top national healthcare ratings, have not led the APCD charge. Minnesota, for example, has a reputation as being a leader in healthcare, but their APCD data domains and reporting authority are very limited, reportedly due to the state's strong health provider community limiting the power of the APCD to produce in-depth analytical reports during the negotiations over the APCDs founding legislation. In contrast to this, the APCD in the

State of Maine has broad authority to collect and report health care insurance data. The APCD is managed as a semi-autonomous agency within the state and serves not only the Department of Insurance, but also the Legislature, by providing data analysis to support legislation and policy setting. The Center for Health Information and Analysis (CHIA) in Massachusetts has a very broad mandate “*to serve a broad, diverse audience. We are a hub, connecting our health care research and data products to policymakers, public and private payers and providers, employers, researchers, and the residents of Massachusetts*” (<https://www.mass.gov/orgs/center-for-health-information-and-analysis>). Although CHIA operates as a state agency to support policy makers, it also will provide data sets to commercial providers for their marketing purposes (following appropriate data use policies).

Political considerations as well as health market structure has played a role in whether states have declined to create APCDs or have severely restricted their operation. Table 2 highlights activities in 17 states to establish an APCD through legislation since 2005, but which have failed as yet to produce sustained activity to develop the APCD. Along with Figure 2, this data suggests an interesting geographical pattern with several possible explanations. Notably, the APCD movement first developed and then spread in the New England states (Maine, Massachusetts, New Hampshire, Massachusetts, Connecticut, Rhode Island). These are states noted for relatively high quality but also high cost health service markets. Moreover, although individual states regulate the health insurance market, residents may live or work in one state and use health services in another, making it valuable for these states to share data to better estimate costs and access to services. The RAPHIC (precursor to the APCD Council) began promoting cooperative agreements and projects in 2007, contributing to this diffusion.

Beyond the pattern of concentration in New England, it is notable that few southern states or northwestern states have successfully implemented and maintained an APCD. While there is not a one-to-one correlation, this pattern is suggestive of political differences among U.S. states, with those states having advanced an APCD having a more consistent liberal, Democratic-leaning voting history and those declining or disbanding an APCD having a more conservative, Republican-leaning orientation. That is, the willingness to fund an APCD and to require APCD reporting for use in health industry regulation maybe indicative of these underlying political divides. There are some exceptions, of course. In the State of Alaska, large chunks of the health care market are not covered by commercial insurance (coming from federally funded systems instead) and thus would not be included in APCD claims data. As a result, an APCD effort would likely have a limited impact on health care market management. The conservative-leaning states of Kansas, Arkansas, and Utah have developed APCDs (with Kansas one of the earliest). Two of the largest U.S. states (California, Florida) are just now developing APCDs, which may be indicative of the large, complex health insurance market in these states that makes the APCD project more difficult to develop and implement.

Beyond state-level influences, a recent decision by the U.S. Supreme Court (*Gobeille vs. Liberty Mutual, 2016*) held that the federal statute governing employee benefits, the Employee Retirement Income Security Act (ERISA), trumps state-mandated reporting by insurers to APCDs. The argument hinged on the undue burden mandated reporting placed on self-funded employee health plans. The petition was filed in 2014, prompting some states that had considered legislation, to wait for the decision to be finalized. Nonetheless, California, Florida, Hawai'i, and Wyoming have each subsequently introduced legislation to create an APCD since SCOTUS announced its decision in March 2016.

Year	State	Context
2005	Wisconsin	An early 2000s stalemate between physician-lobbyists and legislature led to the creation of with Wisconsin Health Information Organization.
2009	Oklahoma	MyHealth Access Network, a statewide health information exchange, also maintains state efforts at an APCD. Those efforts began in June 2009.
2009	Pennsylvania	A 2009 act established a council, PHC4, charged with addressing the problem of increasing healthcare costs in Pennsylvania.
2011	Texas	As a result of Senate Bill 7, 2011, the Texas Institute of Health Care Quality and Efficiency at the Health and Human Services Commission began collecting health data. It was dissolved in 2015.
2011	Montana	A 2011 bill called for a study to be conducted on the viability of establishing an APCD. Three healthcare bills were introduced in 2017, but all were vetoed by the governor.
2011	Iowa	A December 2011 report prepared by the Departments of Human Services and Insurance discussed APCDs in Iowa but didn't explicitly recommend the creation of one. The report was required as part of the passing of HF649, Section 108.
2012	New Jersey	Assemblyman Herb Conaway introduced A-1834 in 2012, which would have called for the creation of an APCD. No action was taken on the bill, though a new bill on transparency was introduced in 2018.
2013	Alaska	A 2013 annual report to the governor from the Alaska Health Care Commission recommended establishing an APCD.
2013	New Mexico	A 2013 bill to study the establishment of an APCD was vetoed by the governor. SB191, introduced in January 2018 would also create an APCD, but has been listed as 'postponed indefinitely.'
2013	Idaho	In 2013, Idaho's 62nd legislature passed House Concurrent Resolution 35 (HCR35) which instructed the ID Department of Health and Welfare to investigate the creation of an APCD. No recommendations were made to move forward with the creation of a database in ID based on that directive.
2013	Kentucky	A 2013 study was presented to the Kentucky legislature on the feasibility of creating an APCD, but no action has been taken on it to date.
2013	Louisiana	The Louisiana Health Care Quality Forum (LHCQ) is a non-profit organization which manages the statewide health information exchange. A 2013 letter indicated it was building an APCD.
2014	North Carolina	North Carolina State University's Institute for Emerging Issues convened two meetings with state representatives and other stakeholders in 2014, focused on creating an APCD. The North Carolina Institute of Medicine task force steering committee released an APCD creation report in April 2017.
2014	Nebraska	NE L76, enacted February 13, 2014, adopted the Health Care Transparency Act and created an advisory committee to evaluate the possibility of creating an APCD.
2014	Illinois	Executive order 14-01 (January 17, 2014) was supported by a \$2M

		grant to develop a plan for building an APCD. Those efforts are no longer being supported.
2015	Ohio	As of June 15, 2015, the Health Policy Institute of Ohio, as part of the Ohio APCD Collaborative, was studying APCD creation.
2015	Michigan	A 2015 bill was introduced which would have created an APCD, but no action was taken on it.
2018	Wyoming	SF0088 was introduced in 2018, which would create an APCD.

Table 2. Past State Efforts at Creating APCDs

4.2.3 *Convergence of APCD form: Collective Actors and Interstate Cooperation*

As with firms in industry as well as other state regulatory agencies, professional associations have developed to support the activities of health data organizations generally, and the development of APCDs in particular. Two organizations that have been influential are the National Association of Health Data Organizations (NAHDO) (www.nahdo.org) and the APCD Council (apcdouncil.org). Through their development and archiving of guideline, handbooks, and other documentation, consulting with specific APCD organizations, and conduct of professional meetings, such collective actors identify or develop possible solutions to common problems and distribute information across organizations.

Depending on their grant funding, members of these organizations may lead efforts to benefit the APCD organizational community as a whole. For instance, the Supreme Court's decision in *Gobeille vs. Liberty Mutual*, 2016, was based on the ERISA law that seeks to shield employer-provided insurance plans from undue burdens in reporting. There are indications in the briefings to the Supreme Court that this case was pursued to protect certain health insurers rather than the employers they serve, as few employers have argued against having their claims data included, and separating out ERISA plan data from other data may be more costly and onerous than including the data. Nonetheless, a possible response to the ruling is to find ways to reduce the burden of reporting by simplifying and standardizing data reporting. This would have the added benefit that insurers that operate across state lines would be able to use the same

formats and systems to provide data to multiple states. Thus, members of the APCD Council, working with private consultants and various APCDs, have worked collaboratively to develop uniform data reporting standards. While a particular APCD might include other data domains beyond claims data, such an effort would help make APCDs more uniform in form along the data domain dimension. This in turn would facilitate articulation of “use cases” and analytical algorithms to conduct analysis.

States also share information about their APCDs and work collaboratively on projects such as standardizing data submission guidelines, as certain large insurers operate across states. These efforts make the APCD data collection and related analyses more manageable and more economically feasible (Office of the National Coordinator for Health Information Technology, 2015). For example, in New England, there have been efforts between New Hampshire, Maine, and Vermont to standardize data collection in order to perform regional analysis of healthcare information. There has also been an effort to standardize measurement on a national level, largely to reduce costs to individual states and enhance analytics. One example is consistent data reporting, which seeks to improve electronic clinical quality measure reporting and to facilitate other data interchange efforts. For example, the Total Cost of Care and Resource Use framework (TCOC) *“is intended to provide step-by-step instructions, along with tips drawn from the experiences of the pilot project participants, to provide entities wanting to report TCOC using a multi-contributor data source with a smoother path while increasing measurement standardization and alignment nationally”* (Network for Regional Healthcare Improvement and APCD Council, 2016: 2). Another project is the effort towards standardization and sharing of the algorithms (data analytics), or analytics warehousing. This may involve standardized analytics within a state, among subsets of states, and across states on a federal level. On the state level,

organizations such as Colorado’s Center for Improving Value in Health Care (CIVHC) provide advanced data analytics. Additionally, CIVHC has partnered with the Human Services Research Institute (HSRI), a third-party organization that provides healthcare analytics to government (including the Maine APCD), creating the potential for national collaboration (Center for Improving Value in Health Care, 2016).

Through these collaborative activities and through the dissemination of solutions across APCDs by professional associations and vendors serving this market (e.g., data infrastructure vendors that support multiple APCDs), the APCD organizational form maintains some degree of similarity in the governance structures and goals across the various state-level instances. These converging influences help shape responses to ongoing challenges and opportunities to health data governance. For instance, one portion of the Affordable Care Act encourages the use of health data to promote “transparency”, that is, to provide some comparative cost data (and ideally, quality data) and access to pricing/costs directly to consumers. Some state agencies, such as CHIA in Massachusetts and the APCDs in Maine and Washington, also take transparency of health cost data as a key governance goal. Not surprisingly, health care market players such as service providers and insurers are cautious about revealing cost details. This is due not only to a desire to protect for competitive advantage but also due to the difficulty in determining and reporting what procedures actually cost. By sharing experiences in conferences, recognizing each others’ accomplishments with “transparency websites”, and sharing algorithmic solutions and approaches, the APCDs reinforce each others’ data governance goals and technical structures in ways that support convergence.

5. Discussion and Conclusions

Governing the vast stockpiles of digitized health data so as to promote data sharing, system-level analytics and transparency, and improvement in health care cost, quality and access, are worthy goals of health care management. The development of APCDs in the U.S. is one example of a wide-scale effort among regulators and policy makers to make health data work on behalf of health care consumers. We have termed this a “movement” because the sustained efforts of multiple field-level actors – the “vocal and well-positioned community participants” such as professional associations, state agencies, state legislators, health care economists, consultants and vendors – have contributed to the gradual diffusion of this organizational form of health data governance over 15 years (from 2003 establishment in Maine until 2018). Nonetheless, this movement has faced substantial pushback from some health industry actors. Insurers are asked to provide claims data, at some cost to the organization and with the possibility of losing market position or power if their data are made public. Providers can feel threatened by the possibility of inaccurate or decontextualized cost data provided under the call for “transparency.” Competing organizational forms, such as not-for-profit or for-profit health data aggregators, may resist government finding for alternative data sources or may seek to control these emerging entities. State legislators may question the value of the APCDs or the data analysis they might provide. Counter to these forces that tend to inhibit emergence is the widely held belief that sharing health data, using data for evidence-based regulation, and promoting cost transparency are essential to bring about improvements in the health care system.

In our report of preliminary findings, we highlight factors that have contributed to emergence of the APCD form, and its convergence in some instances and differentiation in other instances. Table 3 summarizes these. We have identified three levels of analysis for factors influencing the emergence, convergence, and differentiation of APCD organizational forms:

within state, between states, and across states (national). Table 3 summarizes these factors along three levels of analysis: within a state, between states, and across states at the national level. This preliminary categorization will be refined as we continue empirical data collection through in-depth case studies.

Level of analysis	APCD organizational form	Collective field-level actor	Legislation/regulation	Market structure
Within state	Data domains managed Formal/informal relationship with state agencies		Founding regulation Insurance regulation within state State-level focus on health industry regulation	State-level insurance market concentration, variety Relative power of health sector actors Competing data sources
Between states	Shared projects Standardization of APCD claims data	Shared HIT infrastructure actors (vendors)		Regional provider/insurer spillover Cooperative agreements
National level/ across states	National initiatives such as the Health Care Cost Institute striving to create a national APCD or the Agency for Healthcare Research and Quality (AHRQ) sponsoring research	Professional health data management organizations (NAHDO, APCD council)	HHS/CMS policy National data policies (i.e., HIPAA) National regulation (ACA) Grant funding (e.g., the CCIO grant)	Insurance market consolidation and market power

Table 3. Factors influencing the emergence, convergence, and differentiation of APCD organizational forms

Nowhere are the opportunities, challenges, and risks of big data more evident than in the healthcare sector. Our project explores critical questions about how to harness big data resources to enhance society, organizational effectiveness, and individual lives, while also respecting the rights and interests of diverse stakeholders. By focusing on health big data governance, we

extend important debates about individual privacy and rights to control personal data to consider more broadly how organizational forms are taking shape around health big data resources to address various stakeholders' requirements and to engender societal and organizational innovations. Our work advances organizational theory by developing knowledge of what organizational forms emerge and how institutional and sociotechnical factors enable or inhibit novel forms of health big data governance.

Future plans for this work include further analysis of the technological, regulatory, and market conditions that give rise to the APCD organizational form and its emergence in multiple states. To further develop the case, we will review and analyze primary and secondary documents related to APCD developments at the national and state level, including legislation, white papers, conference proceedings, academic publications, and press reports. We will conduct interviews with several dozen national and state stakeholders involved in the APCD movement to investigate in depth their rationale for the APCDs, the steps taken to develop APCD organizations, the facilitating and challenging circumstances encountered, and their expectations and plans for further development. Our approach may also be extended to the analysis and theorizing of other areas of health data governance, such as whether and how organizational forms of governance for patient-generated health data (PGHD) (e.g., data generated by patients from mobile applications and wearable devices outside a clinical care setting) may be emerging. PGHD are rapidly developing as one of the most promising resources for patient engagement and health service improvement, but these data are also the least understood and regulated domains of digitalized personal health data. PGHD are generated in many and varied settings, for instance when patients monitor their own activity or sleep patterns using wearable trackers, monitor and report their blood glucose levels. With rising popularity of mobile health apps and wearable

monitoring devices, patient-generated health data (PGHD) are now rapidly developing outside of clinical settings and outside of regulatory oversight (Blumenthal & Chopra, 2018; Deering et al., 2013; Petersen & DeMuro, 2015; U.S. Department of Health and Human Services, 2016).

Healthcare leaders and policy analysts view these data as a vital resource for health system improvement and innovation, but governing these data resources for patient care or research will be difficult (U.S. Department of Health and Human Services, 2018). Most PGHD are housed within IT vendors' infrastructure or on the individuals' computing device. Moreover, in most cases these data do not fall under existing privacy legislation or health industry regulations.

Limitations of this study include the preliminary nature of our interviews with participants, document review, and attendance at national conferences in which APCD activities were presented/discussed. While several cases are included in our study, it is not necessarily generalizable to other contexts and domains.

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