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State Health Data Organizations

A Framework

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Introduction

State policymakers and regulators are frequently confronted with questions and concerns about the performance of our health care system and find themselves without the necessary information to effectively respond. Data about our health care system—from who it serves to the services it provides, and from the costs we incur to the outcomes we face—are fragmented, narrow and siloed, scattered across federal and state sources. State health care regulatory agencies have historically depended on focused data reporting from regulated entities to support their information needs; few have access to comprehensive market data, leaving gaps in states’ understanding of how health care markets writ large—which are not bound by line-of-business, geography or product type—are functioning.

State health care information gaps have not gone unnoticed. State policymakers across the country—and across the political spectrum—have recognized the need for more coordinated, comprehensive and centralized health care system information and established **State Health Data Organizations (HDOs)**. State HDOs are state-designated agencies or entities that derive information from a diverse array of health care system data to inform policymaking and regulatory decision-making. State HDOs have proliferated over the past two decades without a guiding framework or blueprint, creating a diverse spectrum of entities that share a common purpose, but whose programs, operations and governance can vary significantly.

This brief, made possible by the generous funding of the RWJF and the input of nearly two dozen state HDO and national health data thought leaders, seeks to offer a framework—a first definition—for what a state HDO is, how these entities can support evidence-based policymaking, and what core program, operational and functional elements they comprise.

What Is a State Health Data Organization?

State HDOs are state-designated agencies or entities that derive information from a diverse array of health care system data to inform policymaking and regulatory decision-making. State HDOs may be tasked with broader objectives, including supporting market transparency and competition—or even with the exchange of health information to support clinical care delivery—though this may not be their primary objective.

Over the past two decades, over a dozen entities have emerged that may qualify as a “state HDO,” established with a common goal: to provide those responsible for serving the public good with reliable, accurate and comprehensive information about a state’s health care system and its performance. State HDOs provide policymakers and regulators with a consolidated and comprehensive view of a fractured health care market, centrally collecting and analyzing health care data across purchasers, payers and providers. Their perspectives can be essential for states seeking to address policy issues and priorities that cut across markets, geographies and populations.¹

For example, **state HDOs can provide policymakers, regulators, and the public with information to better understand statewide concerns around:**

- **Health care affordability, costs and cost growth:** What are the primary drivers of health care cost growth for individuals covered by public and private plans? Is cost growth driven by price growth or increases in service utilization? How do prices for health care services vary by line-of-business—and by geography? How are direct costs to the consumer changing over time? How are individuals’ and employers’ health care purchasing decisions changing over time?
- **Health conditions and service utilization:** What is the prevalence of chronic conditions like diabetes and asthma, and how is it changing over time? How are populations—across demographic and geographic characteristics—accessing health care services and interacting with the health care system? Where are network gaps emerging? How are modes of service delivery changing (e.g., telehealth, home-based care)? How frequently are opioids being prescribed, to what populations, following what services, and by what providers?
- **Health care outcomes and disparities:** How are services and interventions impacting health outcomes? Where do service inequities exist, and health disparities persist, across and among populations? Where do variations exist in health care service quality by service provider?
- **Health care system competition and sustainability:** How competitive are our health care markets? Where are health care needs not being addressed? Which health care facilities are in danger of closing, jeopardizing health care access for local residents? Are nonprofit health care facilities serving their community-oriented missions? How pervasive and systemic are health care workforce shortages?
- **Impact of policy and program reforms:** Are alternative payment models improving health care value? What is the impact of public policy and program changes (e.g., Medicaid expansion) on state health care coverage, access and affordability? How could market changes—from closures to proposed mergers and acquisitions—impact access, costs and competition? Where might opportunities arise for reducing administrative costs?

State HDOs are well-equipped to support evidence-based policymaking, real world evidence generation, and contribute to America’s [Learning Health Systems](#).²

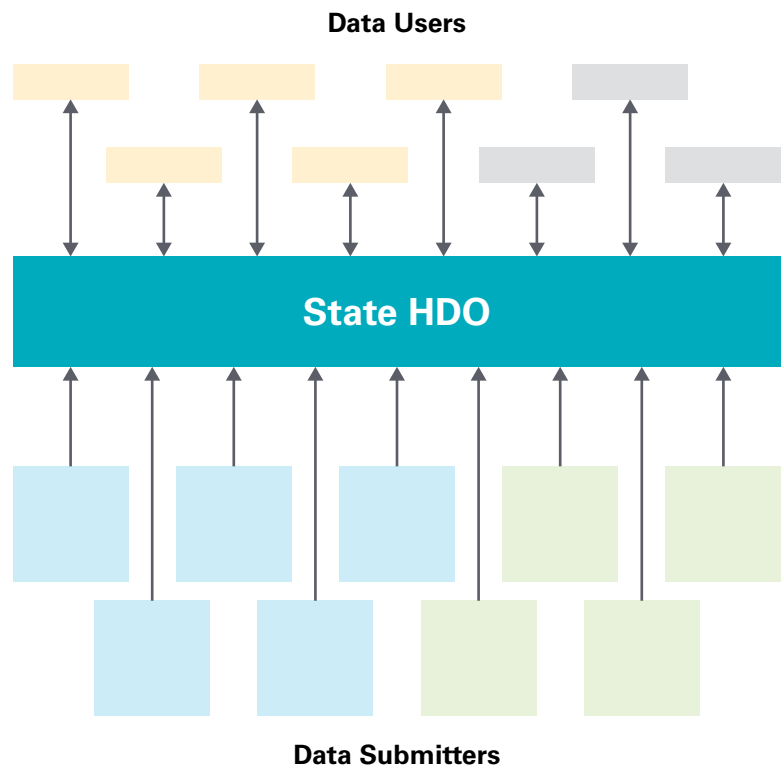
In their role as data brokers, **state HDOs can level persistent health care market information asymmetries between public and private interests, offering the public access to market data and insights at the cost of production, not at the market value of its potential insights.**

State HDOs also offer states administrative and operational efficiencies by centralizing investments in health data and analytic infrastructure, processes and staff, compared to “distributed” data analytic models where such resources are maintained across numerous departments and programs. State HDOs also minimize administrative burden for data submitters, providing a centralized point—and often common methods—for data submission.

However, to be effective, state HDOs must be designed and introduced to complement, not duplicate, existing state health data collection efforts and systems, as they seek to satisfy their state’s unique health information—and system—needs. **To be successful, state HDOs must be structurally braided into a state’s health care information ecosystem, including its:**

- Health Data Legal Authorities:** The collection and use of different types of state health and health-related data is governed under different federal and state laws, which may dictate what data may be collected, by which entities, at what time, and for what purposes. State HDOs should be established in tandem with state regulatory changes that empower the data collection and data use authorities necessary to pursue their missions. Without explicit regulatory authority to collect and use health, state HDOs may confront data submission resistance from private market stakeholders—as well as sister state departments.
- Health Data and Analytic Operations:** State health care agencies have long relied on data reporting from payers and providers to support their core program functions (e.g., rate review, program oversight and accountability). Agency staff may justifiably fear that introducing a new entity responsible for collecting health data into the state ecosystem (or, worse yet, an intermediary into their health data collection processes) could disrupt their existing relationships and submissions, introducing new data timeliness

Figure I. State HDO Market Data Role (Illustration)



and quality concerns. Further, some state agency staff may see a state HDO as a direct threat to their employment, consolidating their roles into another organization. State HDOs must work in coordination with health agency leaders to: clearly define its role in the environment, including where it should be a primary or secondary data collector (i.e., recipient of a data copy) and where it should serve solely as a data broker to state agencies, deferring to agency staff as expert interpreters and reporters; and how it will operate in partnership with peer state agencies to avoid duplication of effort and unnecessary redundancies.

Industry **stakeholders may view state HDOs as unwelcome disruptors and harbingers of greater public scrutiny, and strongly protest their introduction.** State leaders seeking to establish an HDO should be prepared to confront and counter arguments, including:

- Regulatory burden: State HDOs may be labeled as new “regulatory agencies,” poised to add reporting burden to health care organizations operating in the state.
 - Considerations: State HDO regulatory authority is often limited to data collection and reporting, providing transparency to understand how our systems of health are performing, particularly on cross-market issues (e.g., affordability, consolidation and market impact reviews, health equity). Further, state HDOs may be well-positioned to **reduce long-term** regulatory burden on plans and providers by centralizing and streamlining public and private data requests or establishing databases that may be used to support agencies’ future ad hoc data requests; this could be an explicit goal in their founding directives.
- Costs: Establishing a state HDO will only add costs to health care consumers and taxpayers.
 - Considerations: The cost for establishing a state HDO can vary significantly depending on the state’s data, analytic and reporting ambitions (see “Finances”). However, state HDO top-line costs should be, where possible, presented with estimates of the net savings other state health agencies may receive as they divest expensive stand-alone data infrastructure contracts. Assessments of state HDO costs may also consider the potential long-term positive public and private cost effects of data-informed policymaking on market performance—even a fraction of a change in a state’s health care cost growth trends that may be attributable to transparency would represent a savings well in excess of a typical state HDO’s costs.

- **Data privacy:** State collection of health care system data presents a new risk to patient privacy.
 - **Considerations:** America’s deep and justifiable concerns about patient privacy have been weaponized by dominant market actors as stalking horse arguments to combat market transparency, halt the establishment of state HDOs and extinguish data resources like state All-Payer Claims Databases (APCDs). The collection and use of patient identifiable health data must be done in compliance with federal and state law; its access and use should also be publicly transparent and publicly justified. State health agencies and departments, including state HDOs, adhere to federal and state standards for data privacy and security as they seek to derive information to protect the public interest. The same may not always be true in private industry, which often has access to far greater and more revealing stores of America’s health information than those that regulate it, and which regularly seeks to monetize value from its data and data advantage over peers and regulators. Protests against market transparency may be viewed as an effort to preserve structural information asymmetries between those seeking to represent the public interest and those seeking access to the public dollar.

State HDOs are powerful organizations capable of supporting data-driven, evidence-based policymaking and regulatory decision-making and reducing information asymmetries between public and private health care interests. Though established under a common cause, they can vary significantly in the scope of their charge and how they pursue it. In this brief, based on an extensive study of the field, we provide a framework of how state HDOs may be shaped across eight domains to most effectively serve their needed role in our state health data ecosystems:

1. **Mission:** the function, purpose and role of a state HDO.
2. **Statutory Authority:** the powers and duties assigned to a state HDO by law.
3. **Governance:** how a state HDO is established and held accountable for fulfilling its mission.
4. **Data Stewardship:** how a state HDO collects, curates, manages and analyzes its data.
5. **Data Bank:** what data resources a state HDO stewards.
6. **Data and Information Services:** what a state HDO supports.
7. **Operations:** how a state HDO organizes its infrastructure, processes, and workforce.
8. **Finances:** how a state HDO is resourced and sustained.

It is our hope that this framework starts discussion about the value of these enterprises, and how states (and potentially multi-state collaboratives) can establish or mature such capabilities.

State HDO Framework

State HDOs share several common characteristics that make them distinct from other state agencies and organizations that collect and use health care data to advance similar public goals.

1. Mission: The function, purpose and role of a state HDO

State HDOs **serve the public interest** by equipping policymakers and regulators with accurate, timely and actionable information about health care markets and systems and their performance relative to key social and public policy priorities. State HDOs are **publicly accountable through transparent, multistakeholder governance**.

State HDOs are **trusted stewards and brokers** of state health care data and information. State HDOs collect, manage and release data in compliance with federal and state laws. State HDOs are transparent with data submitters about how data may be accessed and used. State HDOs seek to **maximize public data access**, and provide equal access to data among private health care stakeholders.

State HDOs **serve as the agency of record** for metrics about state health care market and system performance, including, but not limited to, indicators of health care coverage, access, needs, utilization, quality, costs, and system and workforce capacity.

Figure II. Model State HDO Mission Statements



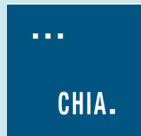
Connecticut's **Office of Health Strategy** (OHS) seeks to implement comprehensive, data driven strategies that promote equal access to high quality health care, control costs, and ensure better health outcomes for the people of Connecticut.



The purpose of [the **Maine Health Data Organization** (MHDO)] is to create and maintain a useful, objective, reliable and comprehensive health information database that is used to improve the health of Maine citizens.

State HDOs are **neutral conveners** of public and private sector stakeholders who are interested in using health care data and information to collectively identify, build consensus around and develop evidence-based strategies for cross-sector or cross-market issues, design effective and targeted health care policies and programs, or manage public programs or interventions.

Figure III. Massachusetts CHIA's Mission and Role as a Convener



Massachusetts' [Center for Health Information and Analysis](#)' (CHIA) mission is to serve as a steward of Massachusetts health information to promote a more transparent and equitable health care system that effectively serves all residents of the Commonwealth. CHIA's data resources and reports are made broadly available to state agencies, providers, payers, health care researchers and consumers.

CHIA brings stakeholders together around its work, in support of its information objectives, and to advance data access and insight availability. CHIA's annual publication on the [Performance of the Massachusetts Health Care System](#), for example, which highlights trends in health care costs, coverage, and quality, serves as foundational material for the state's annual health care cost trends public hearing process, as facilitated by the Massachusetts Health Policy Commission.³

As health care system insights are needed beyond the bounds of what its data and system expertise CHIA can provide, it regularly partners with other state departments and organizations to develop new data resources. In 2023, and again in 2024, for example, CHIA partnered with the nonprofit Massachusetts Health Quality Partners to establish a [Primary Care Dashboard](#), providing policymakers a sought-after, consolidated, and fact-based view of the state's primary care system and its performance.⁴ CHIA has also convened data entrepreneurs in challenges—such as in its 2020's "Price is Your Right Design Challenge"⁵—to test potential solutions to persistent health care system information gaps.

CHIA is responsive to the state's changing policy information needs. As national health system Steward Health Care considered bankruptcy in early 2024, CHIA "actively support[ed] [its] sister agencies...through the provision of data and analysis related to hospital utilization and financial performance, as [policymakers and regulators sought to] stay prepared for whatever situation [would] unfold."⁶ Since the system declared bankruptcy, CHIA has continued to support state planning efforts through the provision of utilization and financial data and analysis.⁷ CHIA is also collaborating with the Executive Office of Health and Human Services and the Department of Public Health to "prepare an integrated workforce dashboard focusing on nursing staff with supply- and demand-side and pipeline data."⁸

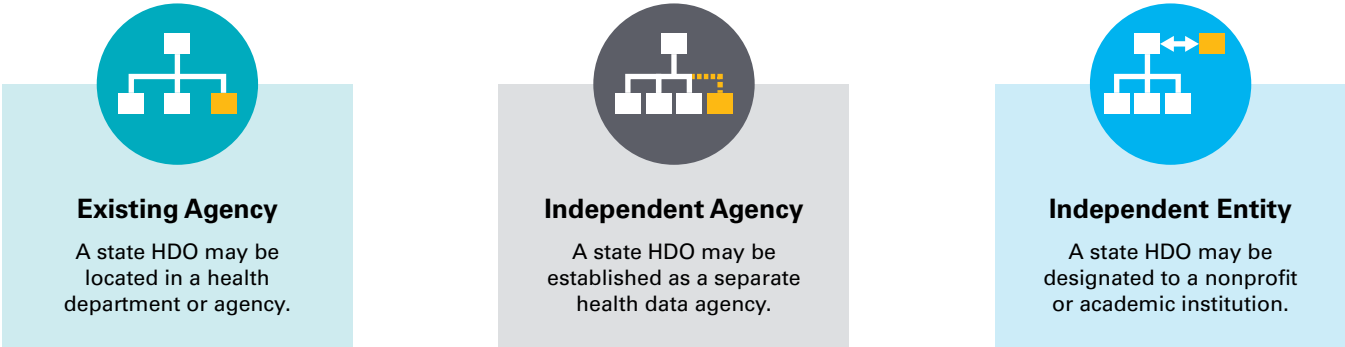
State HDOs may **represent state health data interests** in cross-state, regional and federal efforts to: address health care data and information gaps; understand cross-state market dynamics; and assess implications of policy changes or private market actions (e.g., mergers) on cross-state markets.

2. Statutory Authority: The powers and duties assigned to a State HDO by law

State HDOs are **established and recognized by state law** to collect data and produce information about the health care system for the public good.

State HDOs **do not need to be housed within an Executive agency**. State HDOs may be established and designated as offices within state government agencies, as independent government agencies, or as nonprofits or academic institutions. State HDO capacity may also be established across more than one entity under a shared governance model.

Figure IV. State HDO Entity Types



State HDO **authority for data collection and use is broadly granted by state law**.

Figure V . Model State HDO Laws and Regulations



VHI's statutory authority was established by Virginia law § 32.1-276:

"The General Assembly finds that the establishment of effective health care data analysis and reporting initiatives is essential to improving the quality and efficiency of health care, fostering competition among health care providers, and increasing consumer choice with regard to health care services in the Commonwealth, and that accurate and valuable health care data can best be identified by representatives of state government and the consumer, provider, insurance, and business communities. For this reason, the State Board of Health and the State Health Commissioner, assisted by the State Department of Health and the Bureau of Insurance, shall administer the health care data reporting initiatives established by this chapter." (§ 32.1-276.2)

"The Commissioner shall negotiate and enter into contracts or agreements with a nonprofit organization for the compilation, storage, analysis, and evaluation of data submitted by health care providers pursuant to this chapter; for the operation of the All-Payer Claims Database pursuant to § 32.1-276.7:1; and for the development and administration of a methodology for the measurement and review of the efficiency and productivity of health care providers. Such nonprofit organization shall be governed by a board of directors composed of representatives of state government, including the Commissioner, representatives of the Department of Medical Assistance Services and the Bureau of Insurance, health plans and health insurance issuers, and the consumer, health care provider, and business communities..." (§ 32.1-276.4.A)



MHDO's statutory authority was established by Maine law § 22.1683:

"It is the intent of the Legislature that uniform systems of reporting health care information be established; that all providers and payors who are required to file reports do so in a manner consistent with these systems; and that, using the least restrictive means practicable for the protection of privileged health care information, public access to those reports be ensured." (§ 22.1683.8701)

"The Maine Health Data Organization is established as an independent executive agency...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 this chapter. 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...The organization operates under the supervision of a board of directors...The board shall develop and implement policies and procedures for the collection, processing, storage and analysis of clinical, financial, quality and provider data and prescription drug price data in accordance with this subsection for the following purposes..." (§ 22.1683.8704)



Governor's Office of
PLANNING AND BUDGET
THE STATE OF GEORGIA

OFFICE OF HEALTH STRATEGY AND COORDINATION

Georgia's Office of Health Strategy and Coordination (OHSC) was established by Georgia law § 31.53:

"The General Assembly finds that Georgia faces population and community health challenges. The current health infrastructure must be adapted to adequately integrate state and private resources in a manner that will serve to maximize the state's goals, including improved access to care, effective health management strategies, and cost control measures... There is established within the office of the Governor the Office of Health Strategy and Coordination. The objective of the office shall be to strengthen and support the health care infrastructure of the state through interconnecting health functions and sharing resources across multiple state agencies and overcoming barriers to the coordination of health functions..." (§ 31.53.1-2)

"The General Assembly finds that: (1) Cost of care, diagnostic metrics, care gaps, and best practices are best analyzed with large-scale data; (2) The current data infrastructure must be adapted to adequately integrate state and private resources in a manner that will serve the divergent needs of the state; (3) All components of state data collection and dissemination infrastructure must be more strategic and better coordinated to serve policy makers and health care providers; and (4) A more robust data base will also serve as a platform to provide resources to the public for healthy living and cost transparency...The General Assembly... declares it to be the public policy of this state to unite the major stakeholders of the state's health care system under a common data platform. The public policy of the state will be served by restructuring data silos to inform policy makers, health care providers, and consumers." (§ 31.53.20)

"There is established the GAPCD Advisory Committee for the purpose of making recommendations regarding the creation of the framework and implementation plan for the GAPCD to facilitate the reporting of health care and health quality data resulting in transparent and public reporting of safety, quality, cost, and efficiency information at all levels of health care. The advisory committee shall consist of... The [OHSC] director, who shall serve as chairperson [and 11 other designees]... The director shall seek funding for the creation of the all-payer health claims database and develop a plan for the financial stability of the GAPCD...The objectives of the GAPCD shall be to facilitate data-driven, evidence-based improvements in access, quality, and cost of health care and to promote and improve public health through the understanding of health care expenditure patterns and operation and performance of the health care system...The administrator of the GAPCD shall be the Center for Health Analytics and Informatics of the Georgia Institute of Technology." (§ 31.53.40-45) [Links added]

3. Governance: How a state HDO is established and held accountable for fulfilling its mission

State HDOs are **responsible to multiple authorities**, providing public accountability and checks against excessive political and industry influence. State HDOs may be accountable to:

- Executive authority, through gubernatorial appointment of HDO leadership, state agency regulatory authority to direct data collection and reporting, and budget oversight;
- Legislative authority, through legislative appointment of HDO leadership, legislature-driven data collection and reporting requirements, budget approval and requirements for public testimony; and
- Multi-stakeholder governance boards and steering committees, which may be authorized to oversee or approve of administrative and policy decisions and aspects of data collection, management, release and use.

Multi-stakeholder governance bodies, when publicly and transparently convened, can play instrumental roles in allowing state HDOs to engender trust with:

- Data suppliers, by affirming how state HDO data collection practices will be conducted in accordance with federal and state health data privacy and security standards, and performed to minimize data reporting burden and maximize data utility for proven public use cases; and
- Data users, by designing use cases that address public information needs, conducting analytics using proven and transparent methodologies, and ensuring reporting is accurate, complete and presented with appropriate market context.

State HDOs **serve the public's health care information needs**, as often—though not exclusively—represented by Executive and Legislative stakeholders. While state HDO program priorities may be strongly influenced by Executive or Legislative information needs, consumer, employer, and industry information needs should also be represented.

State HDOs are **transparently governed**. State HDO governance is be conducted publicly, with meetings that are: scheduled with adequate public notice and agendas; open to the public with the opportunity for comment on substantive agenda items; and recorded and posted for the public record. State HDOs produce annual public reports that summarize their program activities and expenditures; and post budget requests for public review and comment.

State HDOs are **nonpartisan health information organizations**. State HDOs **preserve their political neutrality by not taking policy positions** that may be interpreted as being partisan in their presentation.

Figure VI. Example State HDO Governance and Oversight Structures



California Department of Health Care Access and Information (HCAI)

HCAI is a **state department** overseen by a **Director, Chief Deputy Director and deputy directors** with oversight over HCAI divisions. HCAI programs are overseen and supported by a number of statutory committees, councils, commissions, and Boards.⁹



Massachusetts CHIA

CHIA is an **independent state agency** overseen by an **Executive Director** who is jointly appointed by the state's Governor, Attorney General, and Auditor.¹⁰ CHIA is overseen by an 11-member Health Information and Analysis Oversight Council, which guides its research and analytic priorities and approves its budget.¹¹



Center for Improving Value in Health Care

CIVHC is an **independent, not-for-profit organization** based in Colorado operated by a **Chief Executive Officer (CEO)** and overseen by a Board of Directors comprised of public and private stakeholders.¹² The state of Colorado provides the vast majority of CIVHC's annual revenue.

4. Data Stewardship: How a state HDO collects, curates, manages, and analyzes its data

State HDOs **collect the data necessary to support a state’s current and anticipated health data and information needs.**

State HDO **data collection requirements are governed by and developed through a public¹³ process.¹⁴**

State HDOs **establish clear data collection specifications**, including file and field content, format and transmission methods. Data collection specifications are developed in collaboration with data suppliers to minimize administrative burden and with data users to maximize utility. State HDOs may partner with data suppliers to engage in “administrative simplification” activities, identifying the potential for sunseting outdated, unnecessary or duplicative state data submission or reporting requirements.

State HDOs **establish and maintain rigorous data quality assurance processes** to ensure the internal and external validity of submitted data and which incent data quality improvements over time. State HDOs hold data submitters meaningfully accountable for meeting data quality expectations. State HDOs publicly share known data issues of completeness, accuracy and reasonableness with prospective users.

State HDOs **collect, manage and release data in accordance with applicable federal and state data privacy and data security laws.** State HDOs maintain practices that protect data from unauthorized access and use, including performing annual data privacy and security audits and trainings, and by taking preventive measures such as segmenting or eliminating sensitive data after intake to further minimize the risk of breach.

State HDOs **maintain clear, public and transparent data access and release policies.** State HDO data access requirements have standard eligibility and use requirements, review protocols, access fees and appeal processes. State HDOs **allow for public input in advance of the release of any data that may contain Protected Health Information.**

State HDOs **provide public accounting of the data they collect and disclose.** State HDOs publicly disclose what data are collected and which are accessible, to whom, for what purposes, and at what level of detail. State HDOs publicly disclosure what data have been accessed, by what entities, for what purpose, at what cost, to what end, and with what assurance of data destruction (as applicable).

State HDOs **make the data they collect on behalf of the public interest available to public to the maximum extent possible and allowable by law.** State HDOs may offer “tiered” data releases—data products with different levels of detail—to maximize data access, while remaining compliant with federal and state law.

State HDOs **have rigorous data release review processes** to minimize access to legally sensitive information, and to ensure the veracity of related data access requests and the protections that will be maintained, should data be released.

State HDOs may charge the public for data access to reflect the cost of data production, where necessary to support organizational sustainability. **State HDOs do not differentiate costs by the potential value of the data or the prospective data user.**

State HDOs are **analytically transparent**, employing rigorous analytic methodologies, and publishing results with appropriate market context, where possible. State HDOs note data, methodological and analytic limitations in their reporting. Where possible, State HDOs disclose programming code used to support analyses to enable other users to confirm and build on results to the extent practicable.

State HDOs have **capabilities to support data source linkage** and integration.

State HDOs **maintain data and analytic infrastructure that is flexible and scalable** to meet emergent state data and information needs.

Figure VII. Examples of Data Stewardship

MHDO's Data Privacy and Security Practices. MHDO's privacy and security practices and policies for accessing, receiving and storing health data and are consistent with health care industry standards when the data is "at rest and in transit." In addition to detailed requirements for MHDO data access and use, requesting individuals/entities must submit an application to demonstrate an ability to meet the state's requirements for data location and storage, cloud storage security, data transmission processes, data destruction practices, and privacy and security requirements.¹⁵

Arkansas Center for Health Improvement (ACHI) Data Linkage Capabilities.¹⁶ Under the Healthcare Transparency Initiative, ACHI collects and stewards a wide range of data sources from a variety of entities, including the state's APCD, hospital/emergency department discharge data, vital records data, emergency department records, motor vehicle data, cancer registry data and more. ACHI has fostered its ability to facilitate individual-level data linkages across these data resources to derive new and actionable information and insights for policymakers.

5. Data Bank: What data resources a state HDO stewards

State HDOs may serve as: “**primary**” data collectors, acquiring data directly from data suppliers (e.g., payers, providers or other health care entities); or “**secondary**” data collectors, acquiring and compiling data indirectly from federal, national and state sources. State HDOs may also, conversely, serve as data suppliers for other federal and state agencies.

A State HDO’s portfolio of data resources include:

- “**Cornerstone**” data resources, which are foundational to a State HDO fully and effectively pursuing its state health care system information mission, including:
 - [State APCDs](#);
 - [State hospital discharge databases](#);
 - [Hospital financial and cost reporting](#); and
 - [Hospital quality data](#).
- “**Common**” data resources, which are frequently—but not always—acquired, compiled, and stewarded by state HDOs to pursue their missions, including:
 - Household and employer health care access and affordability surveys (e.g., [Massachusetts Employer Survey](#));
 - Health care quality data (e.g., [CAHPS Patient Experience Surveys](#));
 - Health care cost growth benchmarking data (see [Peterson-Milbank Program on Sustainable Health Care Costs’ Benchmarking Playbook](#) and [Manatt “how to” resources](#));
 - Health care workforce data (e.g., [California’s Health Care Workforce Research Data Center at the Department of Health Care Access and Information](#));
 - Health insurance premium and cost-sharing data from federal resources (e.g., [Medical Expenditure Panel Survey Insurance Component](#)) and direct state collections (e.g., [CHIA Payer Data Reporting: Premiums](#)); and
 - Long-term care (LTC) and other health facility report data (e.g., [CA HCAI Long-Term Care Facility Financial Data](#)).
- “**Emerging**” data resources, which are new or high-potential resources that could support state HDOs’ missions, including:
 - [Vital statistics](#) (e.g., birth and death data);
 - Social determinants of health (SDOH) data, which may range from:
 - Compiling and/or linking statistics from public and private social data sources (e.g., HCAI’s [Social Drivers of Health and Preventable Hospitalization Rates Dashboard](#)), to
 - Linking information across state departments to APCD data (e.g., [Denver Housing to Health Project using Colorado’s APCD to assess health care cost savings of supportive housing initiative](#)); to

- Aggregating screening and referral data (e.g., [New York eHealth Collaborative supporting the state’s Medicaid 1115 Waiver](#) implementation).
- Patient safety data;
- Registered provider organization data (e.g., [Massachusetts Registration of Provider Organizations program at the Health Policy Commission](#));
- Clinical data, via clinical data repositories (e.g., [Washington Clinical Data Repository at the Health Care Authority](#)) or as available through [health information exchanges](#) (i.e., as used to support public health purposes); and
- [Hospital price transparency](#) and [payer price transparency](#) data, made available through federal rulemaking.

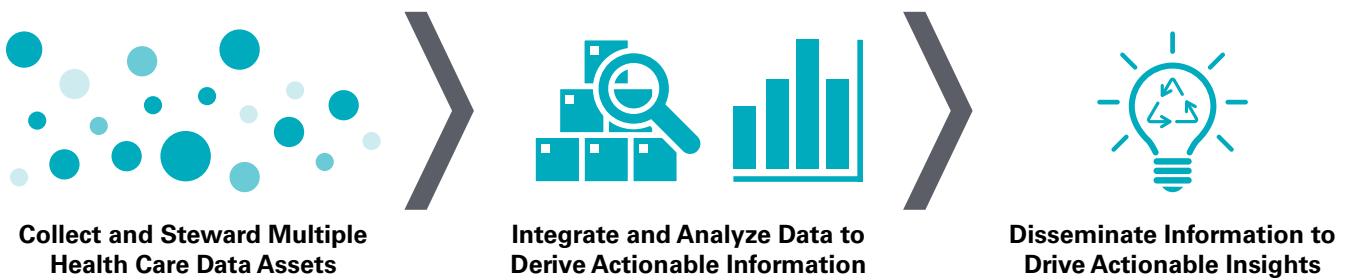
Figure VIII. Health Data Utilities

State HDOs that facilitate or partner with health information exchanges in support of clinical care may also pursue a Health Data Utility (HDU) model that builds on its analytic capacity to “combine, enhance, and exchange electronic health data across care and services settings for treatment, care coordination, quality improvement, and public and community health purposes.” Similar to state HDOs, HDUs benefit from co-located data resources and scaled health data infrastructure. HDUs can be instrumental in supporting [state public health](#) and Medicaid health information needs. For more information on HDUs, see Civitas Networks for Health’ HDU Framework available at <https://www.civitasforhealth.org/health-data-utilities/>.

6. Data and Information Services: What a state HDO supports

State HDOs are **information providers, analyzing and linking data to develop information and reporting that supports evidence-based policymaking and informed regulatory decision-making**, including to target and shape program reforms and monitor reforms' impact on health care system performance. State HDOs may also analyze data to guide payer and program rate setting and contracting and to enhance market and price transparency.

Figure IX. State HDOs As Information Providers



State HDOs are **data brokers, making curated data available for independent internal and external analytic use**, to the extent allowable by law and without discrimination among private entities.

Figure X. Example State HDO Public Tools and Reports

| Statewide Health Care Spending | Prescription Drug Transparency | Commercial Health Care Payments | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
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| <p>Key findings from 2020 health care spending</p> <p>Health care spending for Minnesota residents reached \$106.2 billion in 2020, an increase of 6.4% (to \$38.6 billion) from 2019.</p> <p>If health care spending was unchanged, it will increase more than double from the community, leaving fewer resources for other priorities.</p> <p>The Minnesota Department of Health, Health Economics Program released a report estimating total health care spending for Minnesota residents in 2020 and provided projections for growth in health care spending through 2030.¹⁷</p> | <p>2022 Prescription Drug Price Transparency Report</p> <p>Top 25 Costliest Drugs in Virginia for Commercial Coverage</p> <table border="1"> <thead> <tr> <th>Rank</th> <th>NDC</th> <th>Drug Name</th> <th>Drug Class(es)</th> <th>Number of Prescriptions</th> <th>Total Paid</th> <th>MSRP</th> <th>Net Price</th> <th>Off-invoice Discount</th> <th>Formulary Status</th> <th>Cost</th> </tr> </thead> <tbody> <tr> <td>1</td> <td>1430200101</td> <td>INSULIN</td> <td>INSULIN</td> <td>26,266</td> <td>\$12,763,048</td> <td>\$1,200</td> <td>\$100</td> <td>91.67%</td> <td>Non-Formulary</td> <td>\$12,763,048</td> </tr> <tr> <td>2</td> <td>1430200102</td> <td>INSULIN</td> <td>INSULIN</td> <td>2,726</td> <td>\$10,753,041</td> <td>\$2,479</td> <td>\$1,200</td> <td>50.82%</td> <td>Formulary</td> <td>\$10,753,041</td> </tr> <tr> <td>3</td> <td>1430200103</td> <td>INSULIN</td> <td>INSULIN</td> <td>3,224</td> <td>\$10,717,000</td> <td>\$1,463</td> <td>\$1,200</td> <td>18.26%</td> <td>Formulary</td> <td>\$10,717,000</td> </tr> <tr> <td>4</td> <td>1430200104</td> <td>INSULIN</td> <td>INSULIN</td> <td>10,200</td> <td>\$10,000,000</td> <td>\$1,000</td> <td>\$1,000</td> <td>0.00%</td> <td>Formulary</td> <td>\$10,000,000</td> </tr> <tr> <td>5</td> <td>1430200105</td> <td>INSULIN</td> <td>INSULIN</td> <td>10,200</td> <td>\$10,000,000</td> <td>\$1,000</td> <td>\$1,000</td> <td>0.00%</td> <td>Formulary</td> <td>\$10,000,000</td> </tr> <tr> <td>6</td> <td>1430200106</td> <td>INSULIN</td> <td>INSULIN</td> <td>10,200</td> <td>\$10,000,000</td> <td>\$1,000</td> <td>\$1,000</td> <td>0.00%</td> <td>Formulary</td> <td>\$10,000,000</td> </tr> </tbody> </table> <p>Virginia Health Information annually compiles and reports on specific prescription drug pricing information from health insurance carriers, pharmacy benefits managers and pharmaceutical manufacturers.¹⁸</p> | Rank | NDC | Drug Name | Drug Class(es) | Number of Prescriptions | Total Paid | MSRP | Net Price | Off-invoice Discount | Formulary Status | Cost | 1 | 1430200101 | INSULIN | INSULIN | 26,266 | \$12,763,048 | \$1,200 | \$100 | 91.67% | Non-Formulary | \$12,763,048 | 2 | 1430200102 | INSULIN | INSULIN | 2,726 | \$10,753,041 | \$2,479 | \$1,200 | 50.82% | Formulary | \$10,753,041 | 3 | 1430200103 | INSULIN | INSULIN | 3,224 | \$10,717,000 | \$1,463 | \$1,200 | 18.26% | Formulary | \$10,717,000 | 4 | 1430200104 | INSULIN | INSULIN | 10,200 | \$10,000,000 | \$1,000 | \$1,000 | 0.00% | Formulary | \$10,000,000 | 5 | 1430200105 | INSULIN | INSULIN | 10,200 | \$10,000,000 | \$1,000 | \$1,000 | 0.00% | Formulary | \$10,000,000 | 6 | 1430200106 | INSULIN | INSULIN | 10,200 | \$10,000,000 | \$1,000 | \$1,000 | 0.00% | Formulary | \$10,000,000 | <p>For outpatient services in 2022</p> <p>Hospitals</p> <p>Most Hospitals were paid more than 3-6 times Medicare prices</p> <p>3-6 times Medicare prices 40 Hospitals received 3-6 times Medicare prices</p> <p>2-3 times Medicare prices 15 Hospitals received 2-3 times Medicare prices</p> <p><2 times Medicare prices 25 Hospitals received <2 times Medicare prices</p> <p>CIVHC released a health care payment comparison tool demonstrating how much commercial health insurers in Colorado pay hospitals and Ambulatory Surgery Centers compared to Medicare.¹⁹</p> |
| Rank | NDC | Drug Name | Drug Class(es) | Number of Prescriptions | Total Paid | MSRP | Net Price | Off-invoice Discount | Formulary Status | Cost | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 1 | 1430200101 | INSULIN | INSULIN | 26,266 | \$12,763,048 | \$1,200 | \$100 | 91.67% | Non-Formulary | \$12,763,048 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 2 | 1430200102 | INSULIN | INSULIN | 2,726 | \$10,753,041 | \$2,479 | \$1,200 | 50.82% | Formulary | \$10,753,041 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 3 | 1430200103 | INSULIN | INSULIN | 3,224 | \$10,717,000 | \$1,463 | \$1,200 | 18.26% | Formulary | \$10,717,000 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 4 | 1430200104 | INSULIN | INSULIN | 10,200 | \$10,000,000 | \$1,000 | \$1,000 | 0.00% | Formulary | \$10,000,000 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
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| 6 | 1430200106 | INSULIN | INSULIN | 10,200 | \$10,000,000 | \$1,000 | \$1,000 | 0.00% | Formulary | \$10,000,000 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |

7. Operations: How a state HDO organizes its infrastructure, processes and workforce

State HDOs **maintain the technical infrastructure, staffing and processes (“operations”)** required to support **their roles** as health care information providers, data brokers and conveners.

State HDOs **employ agile teams and development processes** to meet new health information needs.

State HDO **operations are scalable**, capable of supporting new demands for data collection, integration and use as health information demands warrant, making them instrumental partners in addressing emergent health care and public health information needs.

Figure XI. Scaling CHIA Operations to Respond to the COVID-19 Pandemic

During the COVID-19 public health emergency, CHIA provided data, analytic and operational support to Massachusetts’ response effort. Leveraging its core business teams, activities and processes, CHIA quickly deployed data collection streams to understand the scope of the virus’ spread and how the health care system was responding. CHIA augmented data extract and reporting processes to increase the frequency of certain data collections to support the effort, including:

- **Acute Care Hospital Case Mix Reporting**, which was increased from quarterly to monthly to enable faster insights into COVID-19 hospitalization trends; and
- **Health Coverage Enrollment Monitoring**, which was increased from quarterly to monthly to enable faster insights into enrollment trends across markets.

CHIA also launched new data streams focused on LTC facilities to support statewide policy initiatives, including:

- **LTC Reporting**, including weekly COVID-19 surveillance testing, workforce reporting and an ongoing roster of LTC staff/residents; and
- **Rapid Response Team Reporting**, which tracked operational support provided to Rapid Response teams deployed to LTC facilities across the state.

State HDO **technical infrastructure** may be bought, leased or built, and includes, but is not limited to:

- **Administrative systems and customer relationship management tools** to manage staff and contractors, support workflows, engage with data requestors and communicate with stakeholders.
- **Data systems and platforms** that allow for the secure collection, curation, management, normalization, integration and analysis of various data resources in alignment with specific business and technical rules. State HDO systems allow for the creation of segmented production and analytic environments with rigorous access controls and are scalable and modular, allowing for component enhancements without impacting overall system performance or integrity.

- **Programs, tools, groupers and applications** to support data de-identification and linkage to derive new population and system insights (e.g., tokenized or hashed member and provider identifiers, data groupers), and to support the organization’s data stewardship, access and service responsibilities.
- **Analytic, statistical and visualization applications** to support accessible and meaningful reporting (e.g., SAS, STATA, R, Tableau).

State HDOs **have business, legal, technical and analytic staff** as full time employees or dedicated contractors who are familiar with health care information technology infrastructure, security and analytic concerns, including, but not limited to:

- Business leaders who understand how health care data and information can directly and indirectly benefit state stakeholders.
- Data and analytic experts who understand how various health care data resources may be used to meet the information needs of state programs and products, the legislature, and the public.
- Product experts who can advise on the design of data releases, dashboards, reports and other external deliverables to ensure data is being translated and presented in a manner that is accessible to a targeted audience.
- Technical and system experts who can establish and maintain:
 - Protected and secure data environment in alignment with federal and state law and industry standards.
 - Processes to effectively collect, curate, manage, integrate and transmit data.
 - Analytic environments for internal data users.
- Legal experts who can ensure data is being collected, managed, used and released in compliance with federal and state laws.

State HDO **contracted staff may be significant**. Contractors can provide state HDOs with short-term or specialized support for their data systems, data intake, management, and curation activities, and more advanced analytic work. Full time employee to contractor staffing ratios vary from four-to-one to nearly one-to-one, depending on state HDO leadership staffing philosophy, enterprise staffing needs, and long-term budget outlook.

Figure XII. Examples of State HDO Staffing (Approximate)

| Organization | Approximate FTE Count |
|--------------------------------------------------------------------|----------------------------------------|
| Maine Health Data Organization (MHDO) | <10 employees (FY 2022) |
| Arkansas Center for Health Improvement (ACHI) | ~45 employees (FY 2022) ²⁰ |
| Colorado Center for Improving Value in Health Care (CIVHC) | ~45 employees (FY 2022) |
| Massachusetts Center for Health Information and Analysis (CHIA) | ~150 employees (FY 2024) ²¹ |
| California Department of Health Care Access and Information (HCAI) | <150 employees (FY 2024) ²² |

8. Finances: How a state HDO is resourced and sustained

State HDOs **require sustained funding** that is insulated from political and industry pressure, changing policy priorities and economic fluctuations to effectively pursue their public missions. State HDOs are vulnerable to budget cuts given their lack of direct consumers and constituencies, challenges in quantifying the direct value of their services, and the long-term investments in market transparency and accountability they support.

State HDOs **receive most of their funding through state General Fund dollars**, frequently sourced by assessments on payers and providers, but may receive additional revenue from:

- Federal Medicaid matching funds;
- Interagency service contracts;
- Data licensing and access fees;
- Analytic fees and contracts; and
- Philanthropic grants.

Figure XIII. Examples of State HDO Financials

| Organization | Approximate Annual Operating Budget | Description |
|---------------------------|----------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| ACHI | ~\$8 million (FY2022) ²³ | ACHI's receives funding from the state general fund and federal and private grants. |
| Maine HDO | ~\$2.1 million+ (FY2024) | MHDO's operating budget is authorized by the State Legislature in its biennial budget, then assessed—by varying proportions—on hospitals, payers, non-hospital health care facilities and Third-Party Administrators. ²⁴ |
| Massachusetts CHIA | ~\$39.0 million (FY2024) | CHIA's operating budget is defined by the Legislature, with its revenue funded by an assessment on local acute hospitals, ambulatory surgical centers and payers. ^{25,26} |
| VHI | ~\$12.2 million (FY2023) ²⁷ | VHI receives funding from government appropriations, contracts with hospitals and payers, and income from other projects, sales and sources. ²⁸ |

State HDO **financial sustainability requires regular engagement with executive and legislative leaders** to ensure information needs are being met, strong and transparent governance, the quantification of and/or documentation of the value of data to state departments and other data and information users.

Conclusion

This State HDO Framework offers a definition of what a state HDOs is and an assessment of what its structure and operations should comprise to effectively pursue its mission. States should consider the framework as well as the experiences of early state HDOs to guide their own strategic vision-setting, considering:

- How can our state establish an HDO that best reflects and serves our local policy and program health information priorities?
- How can our state establish an HDO that enhances the work of other health care agencies and departments, and contribute to Learning Health Systems and the generation of real world evidence?
- How can our state establish an HDO that reduces the administrative burden of data suppliers, allowing for prior manual reporting to be sunset or streamlined?
- How can our state protect an HDO from external influence, while maintaining a governance structure and financial accountability that ensures its work advances the state's health information needs?
- How can our state pair or integrate our data resources to better understand market performance or the changing health of their populations?
- How can our state ensure that our health data collection, management, and release policies are compliant with federal and state laws and the latest industry standards? Where can we introduce safeguards to further protect patient data from unintended access or unintended use?

State HDOs, if effectively designed and sustainably financed, have the potential to provide state policymakers and regulators a fact-based foundation on which rigorous policy debate can occur on behalf of the public good.

Appendix: Interviewees

| Name | Title |
|---------------------|------------------------------------------------------------------------------------------------------------|
| Ray Campbell | Former Executive Director, Massachusetts CHIA |
| Scott Christman | Chief Deputy Director, California HCAI |
| Karynlee Harrington | Executive Director, MHDO |
| Kristin Paulson | President and Chief Executive Officer, CIVHC |
| Jo Porter | Co-Director, APCD Council |
| Kyle Russell | Chief Executive Officer, VHI |
| Caitlin Sullivan | Deputy Executive Director, Massachusetts CHIA |
| Dr. Joseph Thompson | President and Chief Executive Officer, ACHI |
| Michael Valle | Chief Information Officer, California HCAI |
| Vicki Veltri | Senior Policy Fellow, National Academy for State Health Policy; Former Executive Director, Connecticut OHS |

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