

A Health Information Blueprint for Missouri

Prepared for the Midwest Health Initiative

This report was funded by Missouri Foundation for Health

ACKNOWLEDGEMENTS

The Midwest Health Initiative expresses its gratitude to the hundreds of Missourians that provided insights to this Health Information Blueprint, the members of the project's Thought Leadership Panel, consulting team, and its funder, Missouri Foundation for Health.

Linda Brady

The Boeing Company

Dave Cook

*United Food & Commercial Workers,
Local 655*

Milt Ehly

Bass Pro Shops, Inc.

Debe Gash

*Saint Luke's Health System, Kansas
City*

Cathie Farroll

StratCommRx

Kelly Ferrara

StratCommRx

Charles Hawley

*National Association of Health
Data Organizations*

Jeffrey Howell

Missouri State Medical Association

Jacqueline Hutchinson

Consumer Council of Missouri

Bernadette Inskip

*United HealthCare, Missouri and
Central/Southern Illinois*

Larry Jones

*Missouri Center for Public Health
Excellence*

Sam Joseph

Missouri Primary Care Association

Karen Joynt-Maddox

*Washington University in St. Louis,
Institute for Public Health*

Robert Knodell

*Acting Director, Missouri Department
of Social Services*

Kirk Mathews

MO HealthNet

Douglas McCarthy

Issues Research, Inc.

Judy Muck

Missouri Consolidated Health Care Plan

Josephine Porter

*APCD Council and the University of
New Hampshire Institute for Health
Policy and Practice*

Holly Rehder

Missouri State Senator

Qiana Thomason

Health Forward Foundation

Norm Thurston

*National Association of Health Data
Organizations and the APCD Council*

Heather Lasher Todd

StratCommRx

Sheldon Weisgrau

Missouri Foundation for Health

Ron Whiting

KC Health Collaborative



MIDWEST HEALTH INITIATIVE

May 25, 2022

To our valued community partners,

Statewide all-payer claims databases (APCDs) continue to capture national interest, with 26 states having implemented or started implementation of these health information systems. By including both public and commercial claims, an APCD allows policymakers and other health care stakeholders to access better and more comprehensive data; improve quality health outcomes; and promote equity through the consideration of social determinants of health. All of these strengthen the ability of those that use, provide, and pay for health care services to make informed decisions.

The Need for an APCD: During the last decade, the Midwest Health Initiative (MHI) has built and sustained the largest, voluntary, commercial payer claims dataset for the state of Missouri and the surrounding metropolitan areas. Guided by leaders from the region's largest health plans, health systems, and health care purchasers, MHI has had success in leveraging trusted information and shared accountability to solve the most pressing health care challenges, while balancing considerations for access, quality, and cost. All Missourians could benefit if this system were to expand to include claims paid by all payers, not just the commercial sector.

The Research Project: In 2020, MHI leaders and community partners expressed a shared interest in the creation of an APCD for the state of Missouri. Funded by Missouri Foundation for Health, independent consultants sought insights from over 270 Missouri constituents. The resulting *Health Information Blueprint for Missouri* provides a framework for stakeholder engagement, use cases, governance, funding, and technical considerations to build a valuable health information asset for our state. Objectives of this project included:

- 1) Understand current health information organizations and assets in Missouri,
- 2) Assess the appetite for the development of an APCD for the state, and
- 3) Identify collaborators and champions for achieving this vision in the future.

We are grateful to all who contributed to the report's content. As a Centers for Medicare and Medicaid Designated Qualified Entity, and with access to existing commercial claims data, MHI stands ready to share insights; work collectively with others toward better health and higher value health care; and support or lead efforts to realize an APCD able to serve all Missourians. We look forward to receiving feedback to inform next steps. Please contact MHI Executive Director, Louise Probst, for further information, to offer suggestions, or to lend your support.

Warm regards,

Beverly Propst, MHI Board Chair
Senior VP of Human Resources
Graybar Electric Company, Inc.

Jeff Karrenbrock, Past MHI Board Chair
Senior Director, Business Development
Core & Main, LP

A Health Information Blueprint for Missouri EXECUTIVE SUMMARY

Vision: A health care environment where everyone has timely information to make decisions

The health care system serving Missouri contains many strengths as well as opportunities for improvement. The unrealized improvement opportunities prevent the system from performing as well as it could for Missourians. Research conducted in 2021 for the development of this report revealed an appetite among Missouri stakeholders for access to better and more comprehensive health care information to improve decisions related to health care access, quality, cost, and overall population health, which together can contribute to a stronger and more vibrant economy (Figure 1). To meet this need, this report offers a Health Information Blueprint (Blueprint) for advancing an information-rich environment for health care decision making in Missouri.

Figure 1. Goals of a Health Information Infrastructure for Missouri



As a first step, the Blueprint outlines a process for establishing a statewide all-payer claims database (APCD) as a shared resource for improving health care value, equity, and outcomes in Missouri. An APCD offers a broad view of health care by aggregating data from commercial payers and the Medicaid and Medicare programs, while protecting patient privacy. This proven model is currently available or under development in half of the states. By following a defined path with a menu of choices based on the experience of existing state APCDs, Missouri can create a workable approach that meets its needs and appeals to Show-Me State leadership and residents.

REVISED AFTER PUBLIC COMMENT

The Blueprint development is sponsored by the [Midwest Health Initiative](#), a multi-stakeholder nonprofit that aims to improve health and health care value. The project was funded by [Missouri Foundation for Health](#). A Thought Leadership Panel consisting of diverse Missouri stakeholders informed the Blueprint. Their perspectives and input helped clarify the strengths Missouri has to build on, what it lacks in health information, and key considerations to moving forward with an APCD as a core component of a broader health information infrastructure.

National experts on the APCD Council served as a partner to the research team and recommended this Blueprint follow a framework reflecting the wisdom of other states. Building on that framework, the report explores key issues for stakeholder engagement, use cases, governance, funding, and technical build, which together lay a foundation for planning analytics and applications development in a future phase of work. The study team examined components individually and noted stakeholder agreement or dissent, compared stated information needs with available options, and provided Missouri-specific recommendations, which were subsequently reviewed by the Thought Leadership Panel.

Public engagement for this project included outreach resulting in more than 200 completed online surveys and 70 face-to-face interviews, in addition to the stakeholder meetings mentioned above. Such meetings featured directors of APCDs from other states who shared lessons learned with the Thought Leadership Panel. The research team identified consensus on many framework elements.

Directional data from this study underscores multiple strategies that can be implemented to create an APCD that meets a wide range of stakeholder needs (Figure 2).

Figure 2. How an APCD Would Meet the Needs of Missouri Stakeholders



Summary of Research and Recommendations

The following key research findings and recommendations are described more fully in the report, which also includes context, examples, and implications for Missouri.

Stakeholder Engagement

Key Research Findings: Missourians support the creation of a statewide APCD and anticipate using it to enhance decision making. The purposes of a Missouri APCD should be defined broadly to meet diverse needs and translate data into insights that can be used to increase equitable access to care and improve population health and health care value.

Recommendations:

- Heighten awareness of the vision and the purpose for a statewide APCD in ways that meet the broad range of information needs of Missouri stakeholders.
- Engage public sector payers and health plans to ensure Missouri has as comprehensive a database as possible.
- Advance and sustain a robust stakeholder communication process for keeping health information advocates connected around the development of an APCD.
- Sustain a sense of urgency for action by highlighting the opportunity and benefits that will accrue to Missouri and its residents by advancing access to timely health information.

Use Cases

Key Research Findings: Desired use cases would support public reporting, transparency, performance benchmarking, value-based care, Medicaid transformation, quality improvement research, population health, and access to care in rural and underserved communities. A focus on health equity should be given all of these use cases.

Recommendations:

- Prioritize primary use cases for an APCD in Missouri to answer the most pressing questions related to access, quality, equity, and cost of care.
- Align public and private sector information needs early in an APCD planning process to ensure that information from an APCD will meet the complementary needs of decision-makers in both sectors.
- Collaborate with health equity-focused initiatives in Missouri to assess current capabilities for collecting and using data on race, ethnicity, language, disability, and social needs to address health equity and social determinants of health.
- Develop an analytics plan to define both the intended uses of the APCD and parameters for safely releasing data to protect privacy while allowing analysis by Missouri stakeholders.

Governance

Key Research Findings: Stakeholders in Missouri favor a public-private partnership to govern an APCD, managed by an independent, nonprofit entity with a multi-stakeholder board and state engagement. To achieve its potential, an APCD requires comprehensive participation of payers, whether through voluntary or mandated data submission. As a starting point, Missouri can build on the Midwest Health Initiative's current voluntary commercial payer claims database, which is governed by a multi-stakeholder board.

Recommendations:

- Ask State agency and legislative leaders to engage with the private sector to determine a pathway for APCD development and administration through a public-private partnership approach.
- Explore opportunities for the state to support advancement of Missouri's current health information infrastructure.
- Set a realistic goal for data completeness that will help define whether there is a need for moving from voluntary to mandated submission of insured claims data.

Funding

Key Research Findings: Missourians favor a diversified funding stream, including both public and private sources. Federal matching dollars and state budget appropriations hold appeal for building analytical capacity and sustainability of an APCD.

Recommendations:

- Seek diversified funding sources for the development and operation of a statewide APCD in Missouri.
- Explore opportunities for Missouri to apply for federal Medicaid matching funds, and federal grant funds as they become available, to support a statewide APCD.
- Engage with state legislators and officials about the value of an APCD for Missouri and the available federal matching funds.
- Reduce startup cost and lead time by building on MHI's current data infrastructure.

Technical Build

Key Research Findings: Experts urged building deliberately from essential to more advanced uses; engaging with users to identify and prioritize features for accessing information; using open methods, data standards, and common metrics; and adopting policies that assure the protection of data privacy and security. To support health equity-focused initiatives, Missourians expressed interest in expanding data elements included in enrollment files and/or linking the APCD with other sources that provide data on race, ethnicity, language, and disability; social needs and socio-demographics; vital statistics; and the uninsured. Planning for these elements should be in the design of an APCD.

Recommendations:

- Take a staged approach to APCD development in the context of a broader health information infrastructure, starting with the most essential functions while planning for a progression to more advanced use cases over time.
- Engage with users to define key features of usability and prioritize data access needs and means, while assuring proper privacy safeguards.
- Use privacy regulations and industry certification standards as guides to assure privacy and security.
- Tap expertise in the state to help design an effective APCD and its analytical capabilities.

Cross-Cutting Recommendations

- Cultivate trust and seek buy-in among stakeholders across Missouri. Use data to educate and bring people together to address common interests.
- Define clear objectives for using data to meet needs and improve both access and value in Missouri. Start with a core set of data and information to address prioritized issues.
- Communicate the benefits of an APCD for people in Missouri. Educate stakeholders about its privacy and security safeguards as well as its purposes and operation.
- Recognize and be transparent about limitations of claims data. Use data fairly to evaluate performance considering differences in providers, payment, and markets.
- Attract motivated and capable staff to manage and analyze the data. Tap existing data assets in Missouri and learn from expertise around the state.

Following the path laid by industry experts, learning from the experiences of APCDs in other states, leveraging existing data assets and analytic expertise in Missouri, and consistently seeking input from interested Missouri stakeholders will yield a robust, useful APCD – a strong foundation for Missouri’s health information infrastructure.

INTRODUCTION

In 2020, nearly twenty cents of every dollar spent in the United States was for health care, amounting to \$12,530 per person.¹ Despite this, our outcomes consistently fall short as compared to other wealthy countries that spend half as much on average,² suggesting that the U.S. is not getting good value for its investment. Individuals, families, providers, suppliers, businesses, labor unions, public health entities, and elected officials all feel the impact in the way of high premiums, increasing deductibles, less money for other essential goods, and calls for policy changes. As the imbalance widens between what we spend and what we gain – individually and collectively – the need to attain greater value for our investments in health care grows more urgent.

Missouri is fortunate to have many excellent clinicians and medical centers that provide effective and compassionate care. Yet, in aggregate, Missouri's health outcomes lag. Gaps in equitable access to quality, affordable care and associated disparities in health outcomes are reflected in Missouri's rank of 48th on the Commonwealth Fund 2020 [Scorecard on State Health System Performance](#). Additionally, four of five Missouri stakeholders surveyed for this report agreed that "there are some good things in our health care system, but fundamental changes are needed to make it work better."

Data drive decisions. Good data, therefore, should drive good decisions. Yet good data that is inaccessible to citizens, leaders, and decision makers results in delayed or missed opportunities and unmet needs. In Missouri, making good decisions based on solid health care data has long suffered from too much missing data to answer questions such as:

- "Is their cost reasonable compared to others?"
- "Does the provider's quality justify their higher cost?"
- "Can I save money by getting my medication elsewhere?"
- "How can I offer better coverage for my employees?"
- "Who has the answers to my questions?"

One way to support positive change is to aggregate and organize data in a **health information infrastructure** that allows for informed health care decision making across the spectrum of stakeholders, from the kitchen table to the statehouse. Organizing and using health information is a tested, proven, and beneficial investment. It is essential to successful population health, an evolving process that considers the health and health outcomes of groups of people with the purpose of identifying and closing gaps in care.

***"When (data are kept) behind closed doors we can't make the decisions we need to make."
-Missouri Health System Leader***

¹ Centers for Medicare and Medicaid Services, [National Health Expenditure Accounts](#), Dec. 15, 2021.

² The Commonwealth Fund, [U.S. Health Care from a Global Perspective](#), Jan. 2020.

Discussions with Missouri stakeholders suggest a consensus around shared objectives for a comprehensive and trusted health information infrastructure that serves the interest of all Missourians, supports a continually improving health care ecosystem, protects patient privacy, and facilitates smarter health care decisions and efforts to nudge Missouri toward:

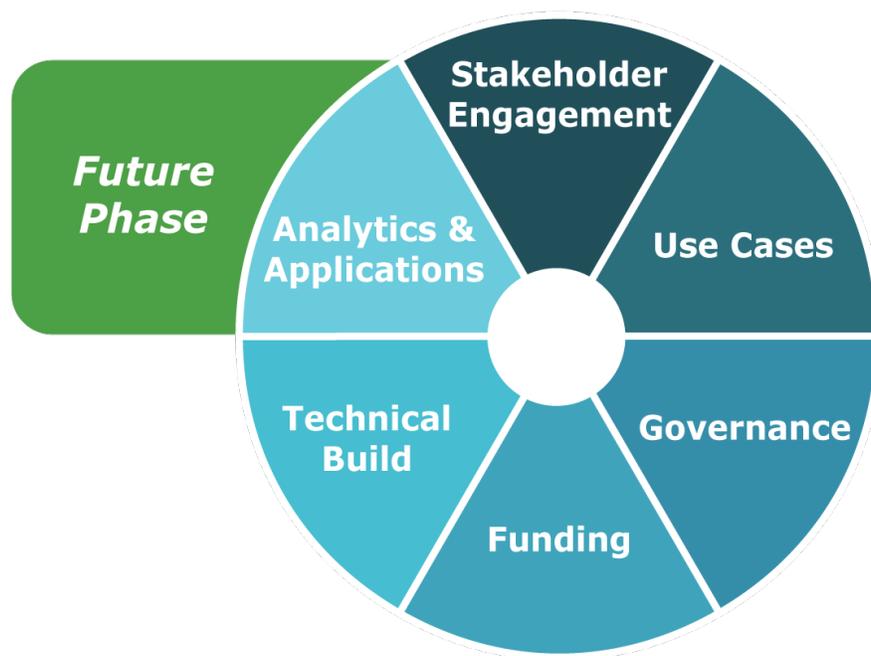
- ✓ Healthier People and Communities
- ✓ Equitable Access to Safe, Clinically Appropriate, High-Quality Health Care
- ✓ Accountability for Health Care Spending and Value
- ✓ A Stronger and More Vibrant Economy.

This report presents a **Health Information Blueprint for Missouri** to realize these objectives. The methodology, the framework, and the ultimate recommendations combine the needs of local Missourians with the expertise of national subject-matter experts.

How This Report is Organized

Project findings are organized and presented in the context of inter-related domains of a framework (Figure 3) adapted from the APCD Council’s [All Payer Claims Database Development Manual](#). These domains encompass concepts relevant to a broader health information infrastructure as appropriate. Five of these domains are defined and explored in the following sections as they relate to Missouri. A sixth domain – analytics and applications development – would be further defined during the implementation phase of an APCD development project to realize agreed on purposes and use cases.

Figure 3. Framework for the Health Information Blueprint



Project Evolution and Goal

This project was undertaken by [Midwest Health Initiative](#) (MHI) and funded by [Missouri Foundation for Health](#). MHI is a Missouri non-profit organization incorporated in 2010 to bring together those who provide, pay for, and use health care to share information and work to improve the quality, affordability, and experience of health care for the people of our region. MHI's multi-stakeholder leaders share a belief in the power of information and collaboration to transform health care (details in Appendix 5).

MHI evolved from a series of a multi-stakeholder conversations hosted by Missouri Foundation for Health in 2006. The goal of these conversations was to identify health information initiatives underway, and explore ways these investments could be aligned to avoid duplication and leverage their collective community benefit. Few electronic health records (EHRs) were fully functional in clinical settings at the time and providers were deep into planning their implementation. Providers and other participants suggested that St. Louis Area Business Health Coalition employers and their health plan partners create a commercial payer dataset that, at some future point, could be transitioned to an **All-Payer Claims Database** (APCD) and aligned with the clinical data enabled by EHRs. Today, MHI stewards a large multi-payer commercial claims dataset representing care provided to 2.2 million people residing in Missouri and its bordering communities.

While MHI's voluntary effort holds great promise, there is a case to be made for broadening its reach and utility by developing a statewide APCD. With intentional design, an APCD can be linked with Medicaid- and Medicare-funded health plans and multiple other sources of data, which make up a larger health information infrastructure to fill gaps in current data assets and enable more robust analyses and learning. By way of this project, MHI sought to assess the interest of others in working toward this goal.

To undertake this task, MHI identified a scope of work, hired consultants, and engaged interested audiences. The result is what you have here: a Health Information Blueprint for Missouri, focusing initially on an APCD to fill a critical gap in Missouri's health information infrastructure. The participants in this process provided insights that required them to be humble, brave, and honest. It also required a realistic review of the health information assets held by Missouri.

Consulting Team and Process

The consulting team, led by Missouri-based [StratCommRx](#), included members from [Issues Research](#), the [National Association of Health Data Organizations](#) (NAHDO), and leaders of the [APCD Council](#). Together they facilitated the project, conducted research, and developed the Health Information Blueprint. The team brings significant expertise into the approaches and successes of other states in creating and finding value in their health information infrastructures. The research team employed four, complementary, information-gathering approaches to develop the blueprint. These included:

1. Statewide leaders representing diverse health care stakeholders were convened as a Thought Leadership Panel. This group of 16 individuals held their first meeting in April of 2021, their final meeting in April of 2022, and met a total of nine times.
2. Online survey of 20 questions, broadly distributed across Missouri from July to September 2021, was responded to by 250 diverse Missouri stakeholders.
3. Insights and lessons from other state leaders with an APCD infrastructure in place were solicited. Several shared expertise with the Thought Leadership Panel.
4. More than 70 leaders, influencers, and advocates across Missouri participated in half-hour to hour-long interviews with the research team. Detailed findings from the survey and interviews can be found in Appendices 1 and 2, respectively.

Missouri's Unique Assets

As mentioned above, Missouri has robust health care delivery systems and practitioner communities. Across the state, there are many assets that add to Missouri's current and potential strengths in advancing its health information infrastructure to improve health, ensuring health equity, and driving even greater health care value. These include:

1. Growing participation by health care providers in health information exchanges (HIEs), which can help improve care by linking their electronic health records.
2. Several leading higher education institutions offering medical schools, health science career training programs, and affiliated researchers interested in making use of claims data from an APCD.
3. Effective public-private partnerships across the state that offer examples for a shared governance structure for an APCD.
4. Active examples of health care professionals coming together with the shared goal of improving population health and managing costs.
5. An established, voluntary, multi-payer commercial claims database for Missouri and its bordering bi-state areas that offers a foundation to build on.

See Appendix 5 for a more detailed overview of these assets and capabilities, including their strengths as well as gaps in data and challenges to be overcome.

What is a State Health Information Infrastructure?

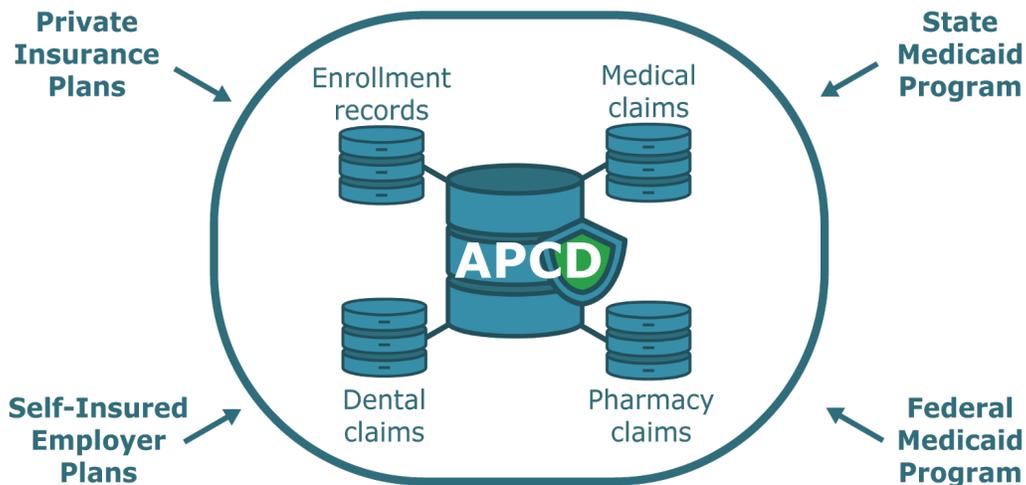
The phrase "health information infrastructure" is used flexibly in this report to describe approaches for bringing health data together to answer questions and solve problems for improving health and health care. These data are typically contained in multiple databases maintained by several entities in the public and private sectors, all of which operate in accordance with applicable state and federal privacy laws and regulations. The components of the infrastructure may vary depending on how and why the data are being used. Some of these components include the following:

State All-Payer Claims Database (APCD): A data system that collects and aggregates adjudicated health care claims (amounts paid for services and related data) from entities that pay for health care services in a state, including private health plans, a state's Medicaid program, and the federal Medicare program (Figure 4). Claims data include information on

diagnoses, services received, and payments (including patient copay amounts) related to care in hospitals, outpatient facilities, and physician offices, as well as prescription drugs dispensed by pharmacies. APCD data are used by a range of stakeholders to understand the health care system, make informed decisions, and seek ways to improve health system performance and outcomes. Data are used for research and analysis in a manner that does not reveal patients' identities.

Figure 4. State All-Payer Claims Database

A statewide all-payer claims database aggregates data from claims for payment of health care services provided to a state's residents



Clinical Data: Most health care providers maintain clinical information on the care of their patients in electronic health records (EHRs), including diagnoses, allergies, medications, problem lists, lab results, and imaging reports. Health information exchanges (HIEs) allow hospitals, doctors, and other health care providers to securely share a patient's electronic medical information, thereby improving the speed, quality, safety, and cost of care. Some health plans are using HIEs as an intermediary to share claims data with providers. Clinical data from EHRs and HIEs have been linked with claims data from APCDs in other states to enable more accurate measurement and identify opportunities to improve health care utilization, quality, and outcomes.

Hospital Encounter Data: Almost all community hospitals submit abstracted information about hospital utilization and billed charges to statewide databases operated by designated data organizations, such as the Missouri Hospital Association's [Hospital Industry Data Institute](#). The data cover inpatient stays and may also include emergency department visits, ambulatory surgery, and hospital outpatient services for both insured and uninsured patients. These databases are used by state governments, the hospital industry, and researchers to examine and improve policy and clinical care delivery. Some states have linked hospital encounter data with their APCD to fill gaps in demographic information and care of uninsured patients, who are not included in an APCD.

Primary Care Encounter Data: Federally qualified health centers (FQHCs) provide comprehensive primary and preventive care to people living in underserved areas, regardless of their ability to pay. They offer an important source of information on the care of uninsured patients, who are not represented in an APCD. Some states have linked their APCDs with FQHC encounter data to capture a more complete picture of health care utilization and access to care for uninsured patients.

Public Health Data: States, including Missouri, collect vital statistics on births and deaths that are used to assess population health trends and outcomes. Other public health data may be collected in disease-specific registries, workforce statistics, or through surveys. For example, cancer registries collect demographic, tumor, and treatment information to support research on cancer prevention and outcomes. State APCD data have been linked with public health data of various kinds to enhance research on health outcomes and to monitor population health trends.

Research Data: Researchers collect various types of health data for use in defined projects. While some projects may create research databases for ongoing use, many are bound by data use agreements for a specific, time-limited purpose.

Census Data: Several states are geocoding their APCDs with sociodemographic information at the ZIP code and census tract level to permit analyses of health care disparities and map the influence of social drivers of health.

To the degree that organizations are able to integrate, align, or connect these data sources for public benefit, the state becomes an information-rich health care environment able to reduce the burden of chronic illness and social disparities in health outcomes and drive higher levels of health system performance, accountability, and value.

How Would a Statewide APCD Enhance Missouri's Health Information Infrastructure?

A statewide APCD would fill gaps in current data assets in several important ways.

- An APCD offers a single, curated source of health care claims data, which creates efficiencies for public and private data users in Missouri. Payers no longer have to provide such data multiple times for specific projects and purposes.
- While other databases may focus on a single setting (hospitals), a single disease (cancer), or a single event (death), an APCD includes complete episodes of care across time and settings including hospitals, doctors' offices, post-acute care, and pharmacies.
- An APCD offers information on costs of care – the amounts actually paid by almost all types of payers for insured patients, which is typically not included in other sources of health data.
- Linking an APCD to other data sources would fill data gaps in both directions, thereby enhancing a health information infrastructure so that it is collectively greater than its individual parts.

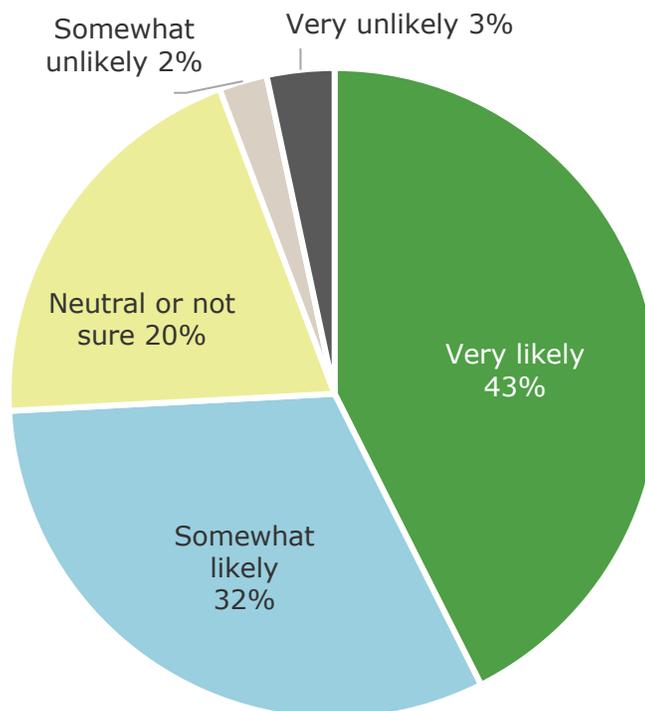
STAKEHOLDER ENGAGEMENT

States across the political spectrum have obtained support for creating APCDs when stakeholders realized the opportunity to use aggregated data as a force for good to improve the health system. A foundational step in developing a statewide APCD is engaging with stakeholders to assess their interests, marshal their support, and articulate a shared purpose — the rationale for why an APCD is needed and what is to be accomplished by creating it. The Blueprint Project addressed this objective by engaging a wide spectrum of interested parties, whose views are reflected in the research findings.

Key Research Findings

There is widespread support among stakeholders in Missouri for creating a statewide APCD as a core component of a health information infrastructure for Missouri. Half of those surveyed were already familiar with APCDs. After the concept was described to them, 75 percent said they would be likely to request data or reports from an APCD if one were established (Figure 5). Many described concrete ways in which they could use data from an APCD to meet information needs and enhance decision making. Enthusiasm was especially notable among employers, providers engaged in value-based care, and quality-improvement researchers.

Figure 5. Survey Responses: How likely are you to request data or reports from an all-payer claims database?



Missouri stakeholders indicate likely benefits from a statewide APCD in many ways, including the following:

Employers & consumers	Become more price sensitive and increase the ability to choose wisely among benefit and care options.
Health systems & physician groups	Manage the cost and improve the quality of care for patients under value-based payment.
Rural & underserved communities	Examine access to care and outmigration of services in order to identify appropriate service levels for the community and design programs to attract and keep providers in the state's most at-risk communities.
Researchers	Discover what works and doesn't work in health care delivery and thereby help create a learning health system.
Legislators & state agencies	Understand health care value and its role in advancing public health and economic vitality for businesses and individuals.
Change agents	Advocate for equitable access and outcomes, while informing initiatives and collaborations to improve population health.
Economic Development Leaders	Monitor gains in health care value. Promote the quality and affordability of health care in Missouri relative to other regions along with the State's active public-private, multi-stakeholder collaboration to continually improve health and the region's health care value.

Implications for Stakeholder Engagement in Missouri

Missouri has a rich tapestry of cooperative efforts among stakeholders to advance various health care priorities, which can inform efforts to build support for a statewide APCD (specific examples are noted in the *Governance* section below.) The Midwest Health Initiative has engaged stakeholders including payers, providers, and plans in creating and using information from a multi-payer claims database to inform constructive dialogue, which offers a strong foundation on which to build.

Recommendations for Next Steps

1. **Heighten awareness of the vision and the purpose for a statewide APCD** in ways that appeal to the collective interests of Missouri stakeholders to meet their broad range of information needs, such as understanding and informing decisions to improve health care value, equitable access to care, and population health. For example, partner with state advocacy groups to highlight how better health care data can empower better understanding and decisions to improve health care access, safety, and quality.

REVISED AFTER PUBLIC COMMENT

2. **Engage public sector payers and health plans to ensure Missouri has as comprehensive a database as possible.** Recruit and explore data contributions from publicly funded health plans, including [MO HealthNet Medicaid Managed Care Health Plans](#) and [Medicare Advantage Plans](#), as well as the traditional fee-for-service Medicaid and Medicare programs. MHI's designation as a Centers for Medicare and Medicaid [Qualified Entity](#) could expedite access to Medicare data for this purpose.
3. **Advance and sustain a robust stakeholder communication process** for keeping health information advocates connected around the development of an APCD as part of a health information infrastructure in Missouri. Build on existing initiatives and research conducted for the Blueprint to identify representatives for each key stakeholder group. Identify key advocates to serve in an ongoing advisory capacity and act upon the vision and learning from the Blueprint. Provide a single point of contact for stakeholders and public seeking information on our process. Develop plain-language materials and identify champions across the state from other organizations who can be tasked with sharing information on the APCD, its purpose, and its benefits. Create a structure and schedule with various opportunities for engagement.
4. **Sustain a sense of urgency for action** by highlighting the opportunity and benefits that will accrue to Missouri and its residents by advancing access to timely health information. When put to use, such information can help transform health care delivery for those in privately and publicly funded programs, and achieve a higher performing health care system that promotes better health and economic wellbeing.

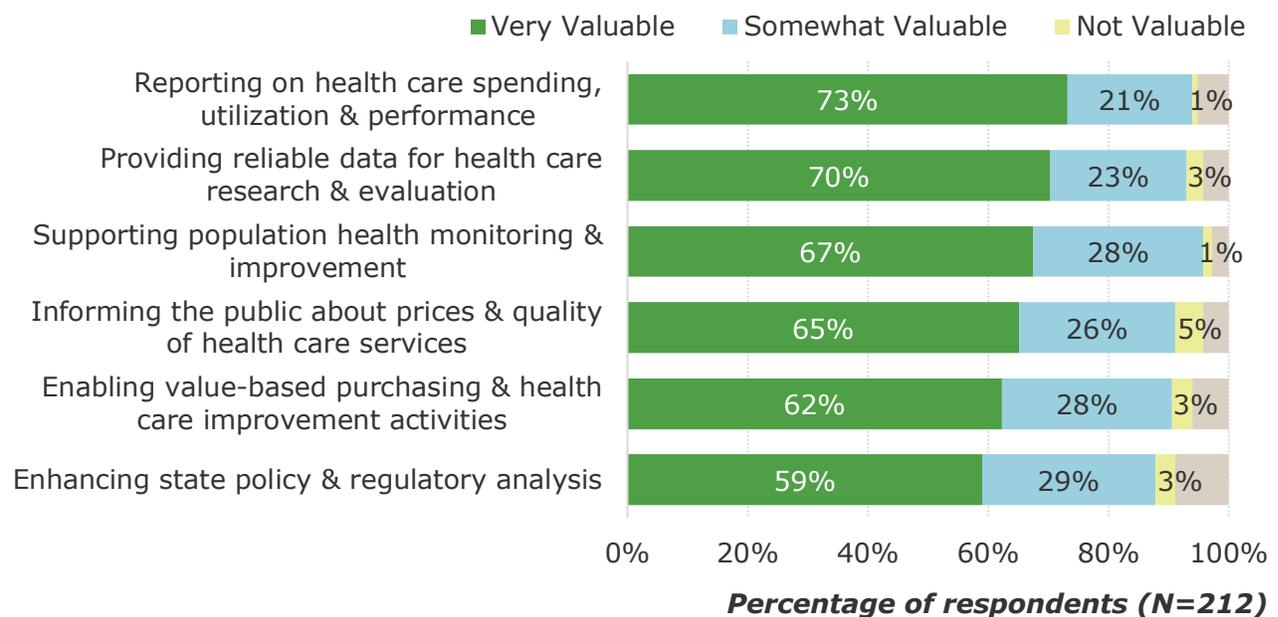
USE CASES

The value and sustainability of any data system is closely linked to the information it provides to inform decision making by stakeholders. This requires defining and prioritizing key use cases to meet the needs of primary users. As articulated by a change agent: "What will be the purpose that will drive action in Missouri?"

Key Research Findings

Missourians valued a range of ways that APCDs are commonly used to assess and improve health care across the country (Figure 6).

Figure 6. Survey Responses: How valuable would each of the following uses of an all-payer claims database (APCD) be for Missouri?



Note: "Not Sure/Don't Know" responses shown in gray. "Other" category not shown.

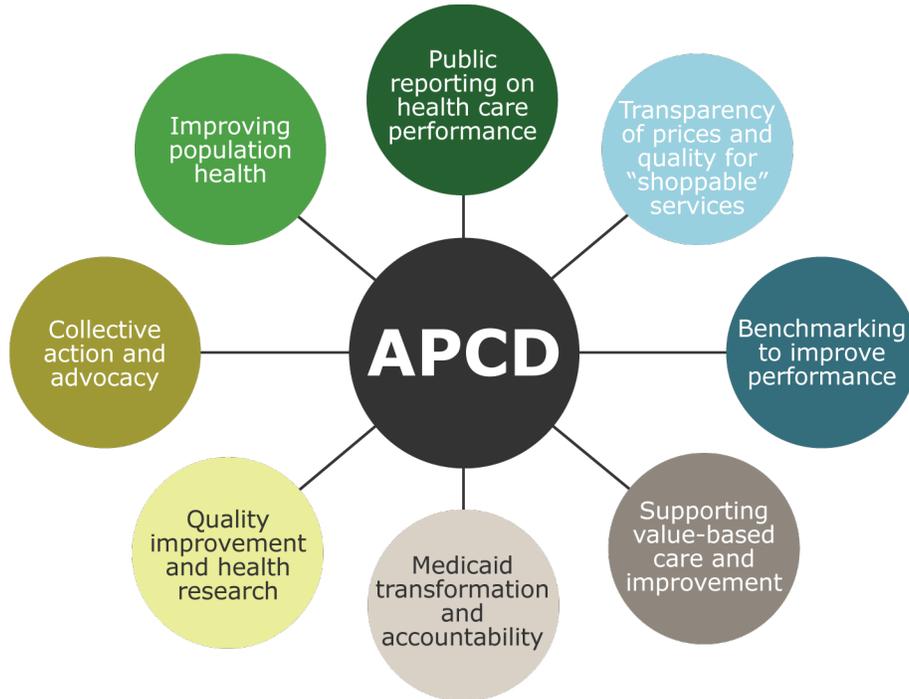
Stakeholders in Missouri described specific ways in which they could use data from an APCD to meet information needs, as well as ways in which an APCD could broadly advance health system improvement in Missouri (Figure 7). These include the following:

Public reporting

Information on health system performance in Missouri would promote greater understanding and improvement at the state and local levels. For example, quantifying geographic variation in cost and utilization of care would show opportunities to improve its value in different regions of the state. Areas with inadequate access to primary care could be pinpointed by examining cases treated in academic medical centers that could have been handled in the community.

Transparency	Publishing information on average prices and quality of elective procedures and “shop-able” services (risk adjusted as appropriate) could help patients assess their care options and empower smart purchasing by employers. An APCD would offer a more complete source of data for this purpose than seeking information (when it is disclosed) on the websites of individual providers and plans.
Benchmarking to improve performance	An APCD could provide both comprehensive and targeted data for providers and plans to evaluate competitive position, identify market opportunities, assess value, discover best practices for learning and improvement, and identify higher performing providers for recognition, referrals, and partnership opportunities.
Value-based care delivery and improvement	Providers and plans in Missouri could use APCD data to identify procedures that have unusual volatility in pricing; educate members on lower-cost, higher-quality providers; model costs to help define contracting strategy, benefit policy, and payment models; and monitor and demonstrate that improvements are being made.
Medicaid transformation	An APCD could support MO HealthNet’s agenda to transform Medicaid by assessing and supporting care coordination across various Medicaid providers, plans, and populations, as well as by advancing their shared efforts to control cost and improve outcomes. For example, the ability to compare Medicaid to commercial insurance would provide insight on payment adequacy, access to primary and behavioral health care in specific areas of the state, and overall program performance.
Quality improvement and health services research	Accessing APCD data longitudinally could enhance the efficiency, validity, and integrity of research and enable more complete outcomes assessment to improve the quality and value of care. For example, APCD data could be used to study adverse effects of prescription drugs or the impact of Medicaid expansion on access to care.
Population health	An APCD could support the efforts of medical groups and state and local public health organizations to better understand the health care needs of populations (e.g., prevalence of people with multiple chronic conditions in specific areas of state), address pressing health challenges in Missouri (e.g., targeting interventions in areas with high use of opioid drugs), and help people stay healthy (e.g., eliminating inequities in the provision of preventive care).
Collective action and advocacy	An APCD could be another tool to help identify gaps in access to care and assess how the health system is performing in rural areas and for historically underserved communities. When linked with other sources of data, an APCD could support efforts to address health equity and impact social determinants of health.

Figure 7. How Missouri stakeholders said they would use a statewide APCD



Implications for Data Use in Missouri

Missouri is home to many existing data assets and sources of analytic expertise that can be tapped and potentially linked or used cooperatively with an APCD to meet stakeholders’ needs in enhanced ways (*see Appendix 5 for descriptions*). Missourians also can adapt ideas from other states about how to use an APCD to advance health care access, value, and population health (*Appendix 3 highlights examples*).

Missouri stakeholders noted a range of capabilities for making use of data. Developing multiple avenues of access (*e.g.*, standard reports, interactive query tools, and public use files) will help ensure that APCD data and analyses are available to all interested audiences in a form that is best suited to meet their particular needs (*see Technical Build*).

Recommendations for Next Steps

1. **Prioritize primary use cases** for an APCD in Missouri by building on input from the Blueprint Thought Leadership Panel (Figure 8) to further define key questions that an APCD should address related to access, quality, equity, and cost of care.
2. **Align public and private sector information needs early in an APCD planning process** to ensure that information from an APCD will meet the complementary needs of decision-makers in both sectors. A preliminary review indicates many potential areas of overlapping interest and need that can be further defined through ongoing discussion.

REVISED AFTER PUBLIC COMMENT

- *Public sector:* [MO HealthNet](#) has immediate and specific health information needs related to evaluating, managing, and coordinating care for the Medicaid population; the Missouri [Department of Health and Senior Services](#) is responsible for assessing opportunities to reduce the burden of chronic illness and advance public health; and the [Missouri General Assembly](#) is tasked with a variety of health economic and policy determinations to advance health and protect the privacy of Missourians.
 - *Private sector:* At a high level, labor and private sector purchasers' goals are to understand and act upon opportunities to improve health and care quality, reduce the use of low-value services, and overcome inequities in care delivery within their enrolled populations. As health care providers in Missouri increasingly engage in value-based care arrangements with health plans and payers, they are seeking better information to manage the quality and cost of care for their patient populations. These goals generally align with public sector priorities.
3. **Collaborate with health equity-focused initiatives** in Missouri to assess and advance current capabilities for collecting and using data on race, ethnicity, language, and disability (RELD), as well as data on social needs to address health equity and social determinants of health. For example, the [Kansas City Health Collaborative](#) is engaging stakeholders to create a common agenda for addressing health equity and social determinants of health. Oregon offers an example of how stakeholders can work with the state to define the ways that RELD data will be collected for effective use.
 4. **Continue to consult with academic, public health, and research communities** in Missouri to further define needs and opportunities for using APCD data. The Blueprint project engaged many of these stakeholders in initial conversations that offer a starting point for ongoing discussions as an APCD development process unfolds.
 5. **Develop an analytics plan** to define both the intended uses of the APCD and parameters for safely releasing data to protect privacy while allowing analysis by Missouri stakeholders (*see Appendix 4 for recommended components*).

Figure 8. Blueprint Thought Leadership Panel Input: What pressing questions do you and stakeholders like you need to answer about these topics?

ACCESS	QUALITY	COST
<ul style="list-style-type: none"> • What are the critical pain points in community access to care and unmet needs for services? 	<ul style="list-style-type: none"> • How can we keep people out of the hospital and healthy through primary and preventive care? 	<ul style="list-style-type: none"> • What are the costs and prices of services including alternative treatments?
<ul style="list-style-type: none"> • How does access to care relate to hospital capacity and use in a community? 	<ul style="list-style-type: none"> • How does performance compare across similar peer groups? 	<ul style="list-style-type: none"> • Why is there variation in cost across providers, or even within a provider across payers?
<ul style="list-style-type: none"> • How does access to insurance affect access to care? 	<ul style="list-style-type: none"> • What is the relationship between patient experience, adherence, and outcomes? 	<ul style="list-style-type: none"> • What is the cost of quality: what is the price of an outcome?
<ul style="list-style-type: none"> • Are insurance networks adequate? Does network adequacy ensure access? 	<ul style="list-style-type: none"> • Are we paying for value? What is the cost-effectiveness of different interventions? 	<ul style="list-style-type: none"> • Are protocols effective (e.g., does an X-ray before MRI help manage cost and add value)?
<ul style="list-style-type: none"> • What does access look like in the “different Missouris”? 	<ul style="list-style-type: none"> • How does performance vary across subpopulations (age, gender, race/ethnicity)? 	<ul style="list-style-type: none"> • How can we make sure we’re using resources equitably?

“Data can be used to tell the story about differential treatment and outcomes. We have an opportunity to use data as lever to have broader conversations. Creating a common table for collective action is what gets attention.” –Missouri Community Change Agent

Case Studies: How State APCDs are Used³

New Hampshire's Transparency Website

In 2007, the New Hampshire Insurance Department launched a [HealthCost website](#), which uses data from the state's APCD to estimate average prices paid to health care facilities for more than 100 common "shoppable" medical tests and procedures. Use of the website has been growing through outreach to employers and links from social media and Google searches, according to state officials.

- Users can learn the total cost of a procedure—including physician, lab, and facility fees—tailored to their insurance coverage, deductible, and co-insurance.
- The website also displays quality measures for the state's hospitals, such as patient experience and infection rates.

An economist estimated that patients saved 4 percent on out-of-pocket costs and insurers saved 5 percent on total costs for imaging services featured on the website (X-rays, computed tomography, and magnetic resonance imaging) compared to services not on the website. This translates to approximately \$7.9 million for patients and \$36 million for insurers over a five-year period. Savings were twice as great for patients responsible for the full cost of the procedure under their deductible.⁴

Analyzing Delivery System Performance in Wisconsin

The [Wisconsin Health Information Organization](#) has honed its APCD data analytic tools over the years to meet the needs of its stakeholders, many of which are integrated delivery systems. Subscribers to the WHIO Intelligence Bank can benchmark the quality and efficiency of health care providers to identify opportunities for improving health system performance and market agility (prices are normalized to mask negotiated fee schedules). They can use the tools to answer questions such as:

- How does this system stack up against competitors?
- What is causing variation in quality of care and resource use?
- What doctors do I need to work with to improve quality and efficiency?

Sophisticated data users can access the tools on a portal or download de-identified data directly into their own IT systems for custom analyses.

³ Source: Douglas McCarthy, [State All-Payer Claims Databases: Tools for Improving Health Care Value, Part 2 – The Uses and Benefits of State APCDs](#) (Commonwealth Fund, Dec. 2020).

⁴ Zach Y. Brown, "[Equilibrium Effects of Health Care Price Information](#)," *Review of Economics and Statistics*, Vol. 101, No. 4 (Sept. 2019): 699–712.

GOVERNANCE

The governing structure for a statewide APCD impacts many other considerations, including funding, technical build, and analytics. It encompasses designating a lead entity or database administrator, defining the rules or policies to guide operations, and endorsing a governing board and/or advisory committee to provide ongoing direction, guidance, and oversight.

There is a strong preference among Missouri stakeholders for State engagement. If State government sponsors an APCD, governance may include authorizing legislation and designation of a state oversight agency. Should the state seek to build on MHI’s current voluntary claims submission or partner with another private sector entity, under a public-private partnership model, the State will need to identify its governance and requirements, and a structure that ensures that APCD assets and its performance accountability are retained by the State of Missouri over time.

Learning from Other States: Options for Missouri

States have adopted varied approaches to governing APCDs depending on their capacity and needs (Figure 9). Most statewide APCDs were established through legislation, while others were created on a voluntary basis by industry leaders in partnership with state agencies. Some states designate a state agency to manage the APCD, typically advised by an appointed committee of stakeholders. In other states, a public-private partnership is convened by a multi-stakeholder nonprofit organization or academic unit, typically under the oversight of a state agency.

Figure 9. Common State APCD Governance Structures

Model	State Agency	Public-Private Partnerships	
State Role or Authority	Statutory creation & state oversight	Statutory creation & state oversight	State participation
Data Collection	Mandatory	Mandatory or Voluntary	Voluntary
APCD Administrator	State Agency	Independent nonprofit or academic unit	Independent nonprofit
Examples	<p>Maine Health Data Organization</p> <p>New Hampshire Insurance & HHS Depts</p> <p>Utah Dept of Health</p>	<p>Arkansas Center for Health Improvement</p> <p>Colorado Center for Improving Value in Health Care</p> <p>Virginia Health Information</p>	<p>Wisconsin Health Information Organization</p>

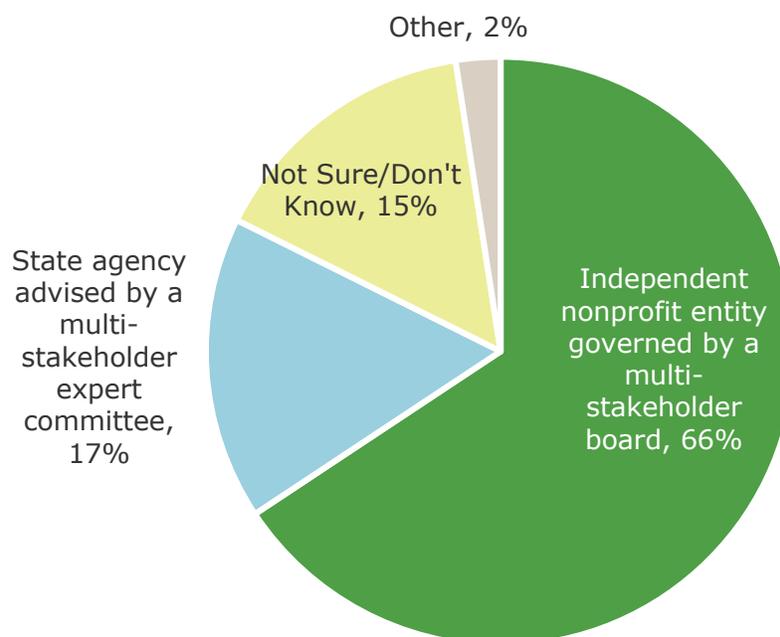
Data submission by payers may be voluntary or required of insurers by statute. (The U.S. Supreme Court [ruled](#) in 2016 that states cannot require participation by self-insured plans

governed by the federal [ERISA](#) law.) Several states started with voluntary data collection and later adopted a statutory mandate to achieve greater data completeness. (Wisconsin’s public employee benefit plan contractually requires participating commercial insurers to submit data to the APCD.) States that rely on voluntary submission may experience gaps in data when payers are not willing to submit all requested data elements.

Key Research Findings

Most Missourians consulted for the Blueprint favored a public-private partnership to govern an APCD in Missouri (Figure 10). There was wide agreement that all stakeholders should be represented in governance or advisory structures. A majority thought that those who govern and manage an APCD should be independent of health care’s financial interest.

Figure 10. Survey Responses: What kind of organization or arrangement would be best suited to operate a statewide APCD in Missouri?



Missouri stakeholders preferred that an **APCD administrator should be neutral and fair, concerned with equity, and transparent and accountable**. They described a desirable governance structure as one that balances stakeholder interests, avoids undue influence by any single group, and ensures the ability to do what's best for the state.

Many noted that **realizing the full benefit of an APCD requires comprehensive participation of payers in data submission**. They saw benefits and challenges of either voluntary or mandated claims submission by insurers. For example, a health plan representative said a voluntary approach would encourage a thoughtful process to attract participation by payers. On the other hand, an employer shared, “We've tried a voluntary

approach and we've gotten as far as we can. You can't get everyone (to participate) without making it mandatory.”

Implications for APCD Governance in Missouri

The preference for a public-private partnership to govern an APCD in Missouri speaks to the success of similar arrangements across the state, as well as the public trust in such a partnership. Examples in other sectors include the [Missouri Technology Corporation](#), [Missouri Venture Forum](#), [Missouri Partnership](#), Jefferson City's [US50/63 Interchange](#), and St. Louis' [CityArchRiver](#) Alliance.

In the health sphere, the state of Missouri partners with employers and insurers in the Midwest Health Initiative, with the University of Missouri's [Center for Health Policy](#) to analyze Medicaid claims data, and with Washington University's [Institute for Public Health](#) to collect and analyze data needed to guide the public health response to the COVID-19 pandemic. The state's [MO HealthNet Oversight Committee](#) may offer a model of how to solicit input from interested stakeholders and provide accountability for such an APCD.

Public and private stakeholders often collaborate at the community level. In the St. Louis region, for example, a [Regional Data Alliance](#) (RDA) acts as a collaborative membership and governing body for local governments, funders, universities, and nonprofit organizations to plan how the region can better use data for community change. The RDA seeks to maximize the impact of existing data efforts by aligning and integrating them with each other.

Recommendations for Next Steps

- 1. Ask State agency and legislative leaders to engage with the private sector to determine a pathway for APCD development and administration through a public-private partnership approach.**
 - The Midwest Health Initiative is willing to serve as the lead entity (administrator) during an APCD development phase. To sustain the progress and goodwill that has been achieved in creating a multi-stakeholder database, MHI is also willing to explore transferring its data assets to another non-profit lead organization, preferably following a competitive bidding process, as long as the lead entity is structured and contractually obligated to meet purchasers' needs for ongoing access to detailed health information. In the event that the state oversees a competitive bidding process for an APCD administrator, MHI may compete for consideration as the lead entity as an independent nonprofit, multi-stakeholder organization.
 - If and when a lead entity is engaged to administer an APCD for Missouri, ensure that the APCD's data and other assets remain accountable to a Missouri governing body; rights to data and data sharing agreements remain under the purview of this governing body; and the lead entity's oversight role can be periodically reviewed and reconsidered by the governing body.

2. **Explore opportunities for the state to support advancement of Missouri's current health information infrastructure.** These may include:
 - a. Participate in a collaborative process to standardize performance measures for medical group reports across public and private programs, as feasible and useful to provider organizations.
 - b. Partner with the private sector to advance, quantify, and publish goals and trends on Missouri's public and private sector investments in primary care, similar to [activities in several other states](#).
 - c. Identify relevant measures and contribute Medicaid data or summary statistics on select measures for community-level and/or statewide reporting on access, quality, and cost of care. Use MHI data to assess performance differences across public- and private-sector programs.
 - d. Share de-identified MO HealthNet Medicaid data on a limited basis with information-based health improvement organizations to improve health care performance in Missouri (*e.g.*, the Kansas City Health Collaborative's work to address social determinants of health, the Quality and Value Innovation Consortium's efforts to reduce hospitalizations among those with congestive heart failure, or MHI's efforts to improve care quality and value).
 - e. Submit a MO HealthNet sample data file to Milliman Inc., MHI's data vendor, in a privacy protected format through a secure transmission portal, for an assessment of the data's suitability to be integrated and aligned with commercial claims data in a way that produces meaningful analysis and actionable insights. Explore the opportunity and define requirements for MO HealthNet to share data with MHI or other organizations under a data sharing agreement that protects patient privacy.
 - f. Encourage MO HealthNet Medicaid Managed Health Care Plans to participate with MHI in making use of data from an APCD for health care performance improvement, which may help satisfy regulatory requirements for Medicaid quality improvement.
 - g. Explore state or federal match funding for an APCD (*see next section*).
3. **Set a realistic goal for data completeness** that will help define whether there is a need for moving from voluntary to mandated submission of insured claims data. *See Virginia case study (below) for an example of how another state approached this task.*

Case Studies: APCD Governance in Other States

Virginia's Public-Private Partnership Experience

A Virginia governor's health reform initiative led to 2012 legislation authorizing an APCD through a partnership between the nonprofit [Virginia Health Information](#) and industry associations representing the state's health plans and hospitals, under the oversight of the state's health department. Health plans voluntarily submitted claims data while the associations provided financial support for the APCD's operation. Under this approach, the APCD collected data representing about 65 percent of the state's insured market, which fell short of a legislative goal to achieve 75 percent participation.

To expand the APCD's scope, the legislature mandated claims submission by health plans and appropriated funds to support the APCD's operation beginning in July 2019. The number of insured lives included in the Virginia APCD increased by approximately one million after the state mandated claims submission and expanded Medicaid.

Washington State: A Cautionary Tale

The [Washington Health Alliance](#), a coalition of Puget Sound employers, providers, and patients, created a multi-payer claims database to support smart purchasing and health care transparency. In 2008, the Alliance began publishing an annual Community Checkup report (now a searchable website) measuring the performance of area medical groups, clinics, and hospitals. Voluntary participation in the database has grown over time to include nearly all commercial and self-insured payers serving the area.

To enhance the utility of a claims database, the Alliance and other stakeholders supported state legislation to create a statewide APCD, on the assumption that the state would build on the Alliance's work. State procurement rules prevented the Alliance from bidding on the state's initial RFP for an APCD administrator. Consequently, the selected contractor developed a separate APCD, with about 90 percent of the same data in both databases. Although the Alliance won a new bidding process in 2019, the goal of creating a single statewide claims database has yet to be realized.

A lesson from Washington State is to avoid duplication of effort by planning carefully and reaching agreement among stakeholders, public and private, on both the intent and the mechanisms for expanding a voluntary claims database into a statewide APCD.

"An APCD could be another key component to add to the state's agenda to transform Medicaid." –Missouri Official

FUNDING

Funding is a key consideration for the development and sustainability of a statewide APCD. Costs for planning, implementation, and maintenance will depend on the purpose and scope of the database and its technical configuration. Funding considerations need to include all aspects of system development, operation, and maintenance.

Learning from Other States: Options for Missouri

A [Commonwealth Fund study](#) of eight state APCDs reported annual core operating budgets ranging from \$800,000 to \$4.2 million, reflecting differences in the scope of their missions and capabilities. Directors of leading APCDs say that realizing full potential requires ongoing investment in capabilities and expertise. States rely on a variety of funding sources for their APCDs, including the following:

State Budget	Most states receive core operating funds for their APCD through the annual state appropriations process. Several get federal help supporting their APCD by applying for a federal match of state Medicaid funding designated to support use of the APCD for improving the operation of the Medicaid program.
Industry assessments or contributions	Some states (e.g., Maine and Massachusetts) assess annual fees on health care providers and health plans based on net patient revenue, premiums written, or a flat dollar amount. In a few states, the private sector voluntarily contributes funding for an APCD and receives access to privacy-protected APCD data in return.
Contracts and data use fees	Most state APCDs charge customers to recover their costs for producing custom datasets, nonpublic reports, and requested data analyses. A few offer subscriptions to the database, to users with the sophistication to make effective use of the data and protect it under data use agreements. Some offer discounts to nonprofit organizations and/or researchers that meet specific criteria.
Grants	Many state APCDs have received federal, state, or private grants to fund the development or enhancement of their APCDs and/or to create analytical capability and reports. The federal No Surprises Act authorized federal grants to support state APCD development, but funds have not yet been appropriated to fulfill this promise.

Key Research Findings

Missouri stakeholders said a diversified funding stream, including both public and private sources, would help ensure long-term sustainability. Many viewed grants, contracts, and data use fees as the most feasible sources of funding. Others urged that data use fees be set judiciously (*i.e.*, on a sliding scale) so they do not pose a barrier to use of the APCD, especially by nonprofit community organizations. While the private sector and foundations have offered startup support for initiatives such as an APCD, there was concern about the adequacy and long-term sustainability of voluntary financing.

A few stakeholders were cautiously optimistic about the possibility of seeking an appropriation from the state legislature, given that an APCD would serve the common good. They pointed to bipartisan support for public-private economic development projects (see *Governance* for examples), a state appropriation to develop the [Show-Me ECHO](#) telehealth network, and the state's pass-through of federal funds to Medicaid providers participating in the [Health Information Exchange Onboarding Program](#).

Implications for Funding an APCD in Missouri

A public-private partnership governance model may offer greater flexibility for seeking diversified sources of funding for an APCD. Some funding sources are contingent on state involvement (*e.g.*, federal Medicaid matching funds and federal "pass through" grants). The voice of employers may be vital to gain legislative support for funding an APCD in Missouri.

Recommendations for Next Steps

1. **Seek diversified funding** sources for the development and operation of a statewide APCD in Missouri
2. **Explore opportunities for Missouri to apply for federal Medicaid matching funds, and federal grant funds** as they become available, to support a statewide APCD.
3. **Engage with state legislators and officials** about the value of an APCD for Missouri and the available federal matching funds. Look into the possibility of seeking a state budget appropriation to support its development and operation.
4. **Reduce startup cost and lead time by building on MHI's current data infrastructure.** Although MHI has received no public-sector funding, it currently invests more than \$600,000 annually to support its data repository and operations.

Developing leading indicators for identifying future health care concerns and emerging trends would benefit all payers." –Missouri Health Plan Leader

TECHNICAL BUILD

The technical build results in the operational and quality assurance protocols for receiving and processing the data that will be used for analytics and applications. Defining data inputs and structure is a key step in the technical build. The construction of a statewide data system is complex and resource-intensive, warranting careful planning with all stakeholders. Setting goals for APCD implementation helps ensure its effective development.

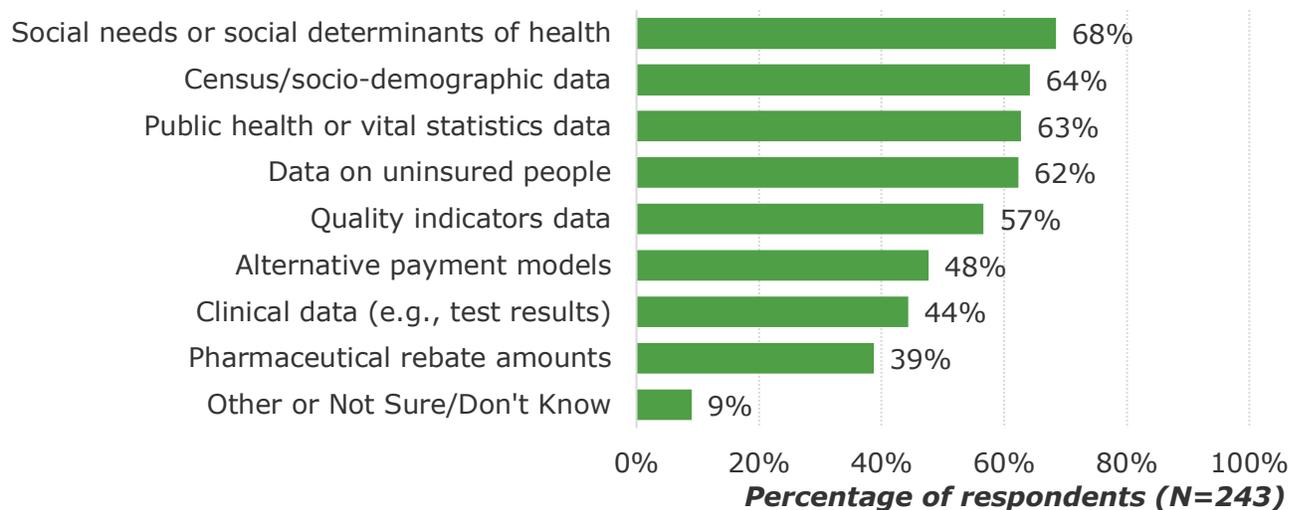
Key Research Findings

Health plans and others urged the use of **agreed-upon standards and definitions, common metrics, and credible risk-adjustment methods** to promote efficient claims data submission and analyses as well as acceptance and uptake of APCD data (see Appendix 2 for details). Many emphasized the need for ensuring data privacy and security, with implications for how data are collected.

There was **wide interest in many other types of data** to be used in conjunction with, or linked to, claims data to broaden the utility of the APCD and the kinds of analyses it can support (Figure 11). For example:

- Race, ethnicity, language, and disability (RELD) data to address health equity,
- Data on social needs to address social determinants of health,
- Clinical data to deepen understanding of quality and outcomes, and
- Data on the uninsured to measure access to care for vulnerable populations.

Figure 11. Survey Responses: Are there other kinds of information that you would like to see included in or linked to a health information infrastructure for Missouri?



Note: Respondents could choose multiple answers.

Implications for Technical Build of an APCD for Missouri

Missouri can benefit from investments already made in standards development and claims data collection in Missouri and across the country. For example:

- The APCD Council has developed a Common Data Layout for standardized claims data submission. All of Missouri’s major commercial health plans currently contribute commercial claims data to MHI using the Common Data Layout standard on behalf of the community. (Gaps in data remain to be filled through a statewide APCD.)
- Health plans serving Missouri already take part in other state APCDs and have developed processes for data submission; risk adjustment and attribution processes have been agreed to and are in place in Missouri.
- Many experienced vendors are competing for technical contracts in this area and have honed their capabilities for serving statewide APCDs.

Recommendations for Next Steps

1. **Take a staged approach to APCD development** in the context of a broader health information infrastructure, starting with the most essential functions while planning for a progression to more advanced use cases over time (Appendix 4 provides a tool to help develop such a plan). Set reasonable expectations of the time and effort needed for APCD implementation and use. The State of California offers an example of how to develop such a [staged APCD implementation plan](#).
2. **Engage with users to define key features of usability** and prioritize data access needs and means, while assuring proper privacy safeguards. Most stakeholders are seeking information derived from data rather than raw data from an APCD. Other states offer multiple avenues of data access to meet varied user needs, such as reports, interactive query tools, and public use files. The [State of Maine](#) offers an example of how to engage with stakeholders for this purpose.
3. **Use privacy regulations and industry certification standards as guides to assure privacy and security**. Understand the differences and pros/cons of becoming a covered entity subject to the federal HIPAA Privacy Rule versus developing policies to protect privacy and security in conformance with HIPAA principles.
4. **Tap expertise in the state to help design an effective APCD** and its analytical capabilities. For example, the Missouri Hospital Association published a [Health Equity Dashboard](#) that analyzes social needs coded in hospital encounter data. Other sources of expertise include the University of Missouri, Washington University, and the Quality and Value Innovation Consortium (*see Appendix 5 for details*). Consider engaging these experts in a technical advisory capacity.

Case Study: State Health Information Infrastructure

Colorado's Health IT Roadmap

In 2021, Colorado updated its [Health Information Technology \(IT\) Roadmap](#) for harnessing and expanding digital tools and services to support the health of Coloradans. Developed by the state's [Office of eHealth Innovation](#) (OeHI) in consultation with stakeholders, the Roadmap recommends policy, technology, and funding solutions to achieve three primary goals by 2024:

1. Coloradans and various stakeholders share data and have equitable access to needed health and social information.
2. Coloradans access high-quality in-person, virtual, and remote health services that are coordinated through information and technology systems.
3. Colorado improves health equity through inclusive and innovative use of trusted health IT and digital health solutions.

The Roadmap articulates "a vision for transforming the state's current patchwork infrastructure into a more cohesive and integrated system...that can better serve all Coloradans." For example, the Roadmap recommends setting up a scalable data sharing platform and standard data sharing agreements that protect individual privacy and facilitate a single-entry point to decentralized systems.

Stakeholders defined common values to align their efforts and guide the development, prioritization, and implementation of strategies to achieve the three goals. These efforts are being stewarded by OeHI, which receives federal funding to support its work, with guidance from an eHealth Commission appointed by the governor, and the cooperation of state and local government agencies and community partners.

"You have to build a group of people who can work with end users to interpret [the data]. Even if you have an excellent front end, it still takes a special person to ask the questions correctly. You need a human with experience listening and translating [requests] into queries and to know when the database can't answer that question." –Missouri Health System Leader

CROSS-CUTTING ISSUES

States face similar challenges in establishing an APCD, as well as unique circumstances that shape their approach to its development.

Key Research Findings

Missouri stakeholders named a range of concerns and potential challenges that should be considered in planning for APCD development as part of a broader health information infrastructure (*see Appendix 2*). For example, they warned against making data collection an end in itself, focusing solely on the cost of care, or promising to accomplish too much too quickly without considering the time needed for implementation. Obtaining legislative support for a statewide APCD was perceived as important for Missouri. Stakeholders also offered a range of advice to overcome these challenges.

Implications for Missouri

Missouri can benefit from lessons other states have learned in addressing common challenges (*see Appendix 3*), while looking to its assets and achievements to draw inspiration for shaping a unique approach to meet the needs of the Show Me State.

Recommendations for Next Steps

1. **Cultivate trust and seek buy-in among stakeholders** across Missouri. Use data to educate and bring people together to address common interests.
2. **Define clear objectives for using data** to meet needs and improve both access and value in Missouri. Start with a core set of data and information to address prioritized issues.
3. **Communicate the benefits of an APCD for people** in Missouri. Educate stakeholders about its privacy and security safeguards as well as its purposes and operation.
4. Recognize and **be transparent** about the advantages and limitations of claims data. Use data fairly to evaluate performance considering differences in providers, programs, payment, and markets.
5. **Attract motivated and capable staff** to manage and analyze the data. Tap existing data assets in Missouri and learn from expertise around the state.

CONCLUSION

Missouri is well positioned to leverage its existing health information assets, including the foundational work of the Midwest Health Initiative, to create a fully functional and comprehensive APCD that would benefit many stakeholders and the public. A statewide APCD would enhance efforts across the state to establish many components of a broader health information infrastructure. Developing a capability for linking the APCD to other sources of data is a worthy goal that would allow the APCD to play a vital role in burgeoning efforts to improve health equity in the community.

With intentional and concerted effort, Missouri could become a national leader in harnessing data to create a health care environment where everyone has timely information to make decisions. Achieving this vision would facilitate the conditions for a well-functioning private market, dynamic community collaborations, and effective public programs so that each and all fulfill their potential for promoting improved health and economic prosperity in Missouri.

REFERENCES

- APCD Council, [All Payer Claims Database Showcase](#): States Leading by Example (n.d.).
- APCD Council, [APCD Common Data Layout](#) (n.d.).
- Roxanne Andrews, "[Statewide Hospital Discharge Data: Collection, Use, Limitations, and Improvements](#)," *Health Services Research*, Vol. 50 (Supplement 1): 1273–99, August 2015.
- Matthew Fiedler and Christen Linke Young, "[Federal Policy Options to Realize the Potential of APCDs](#)," USC-Brookings Schaeffer Initiative for Health Policy, October 2020.
- Rebecca Gourevitch and Ha Tu, [Moving Markets: Lessons from New Hampshire's Health Care Price Transparency Experiment](#), California Health Care Foundation, April 2014.
- Alyssa Harrington, [Releasing APCD Data: How States Balance Privacy and Utility](#), Freedman HealthCare LLC, March 2017.
- Lucy Hodder, Jo Porter, Denise Love, et al., [Model All-Payer Claims Database Legislation](#), APCD Council and West Health Policy Center, May 2015.
- Keziah Imbeah, Paul Howard, Rebecca Brandes, et al., [Roadmap for Race, Ethnicity, and Language \(REL\) Data Collection and Use in Connecticut](#), Connecticut Health Foundation and the Institute for Healthcare Improvement, Spring 2021.
- Kevin Casey McAvey and Alisha Reginal, [Unlocking Race and Ethnicity Data to Promote Health Equity in California: Proposals for State Action](#), Manatt Health, April 2021.
- Douglas McCarthy, *State All-Payer Claims Databases: Tools for Improving Health Care Value*, [Part 1—How States Establish an APCD and Make It Functional](#); [Part 2—The Uses and Benefits of State APCDs](#), The Commonwealth Fund, December 2020.
- Office of the National Coordinator for Health Information Technology, "[What is Health Information Exchange?](#)" U.S. Department of Health and Human Services, July 2020.
- Jo Porter, Denise Love, Amy Costello, et al., [All Payer Claims Database Development Manual: Establishing a Foundation for Health Care Transparency and Informed Decision Making](#), APCD Council and West Health Policy Center, March 2015.

APPENDIX 1: Survey Research Findings

Methods

A 21-question survey instrument was developed in collaboration with the Midwest Health Initiative (MHI) and refined with input from the Health Information Blueprint (HIB) Project Thought Leadership Panel.

3,436 Missouri stakeholders identified by MHI were invited to take the survey via email. The survey was administered via Qualtrics from July 7 to Sept. 17, 2021. Periodic reminders were emailed to non-respondents during the survey administration period.

250 people started the survey and 210 completed all questions. Seven employees of MHI or the St. Louis Area Business Health Coalition were excluded from the analysis, yielding a final count of 243 respondents (among whom 204 completed all questions).

Results were analyzed using Qualtrics and Excel. Respondents who didn't answer the stakeholder question were attributed to a category based on invitation email address; those who selected "other" were reassigned to appropriate categories based on text response. The legislator category was excluded from subgroup analyses due to small sample size. Significance was assessed at 0.5 standard deviation from the mean.

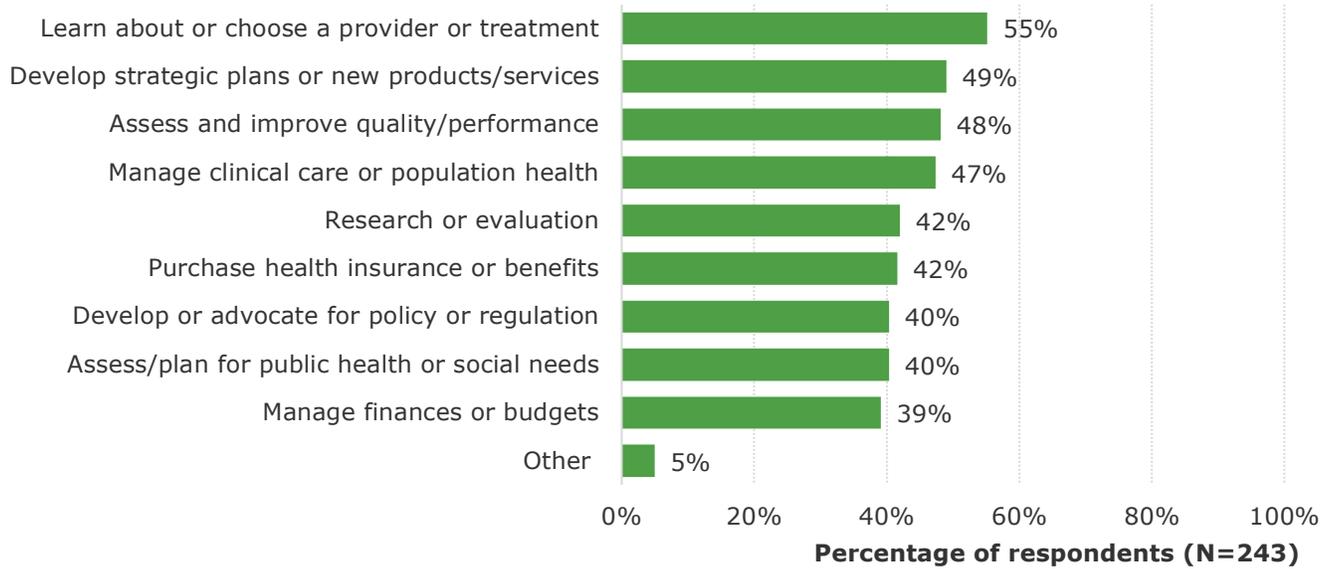
Findings

A1.1. Which best describes your stakeholder role or affiliation?



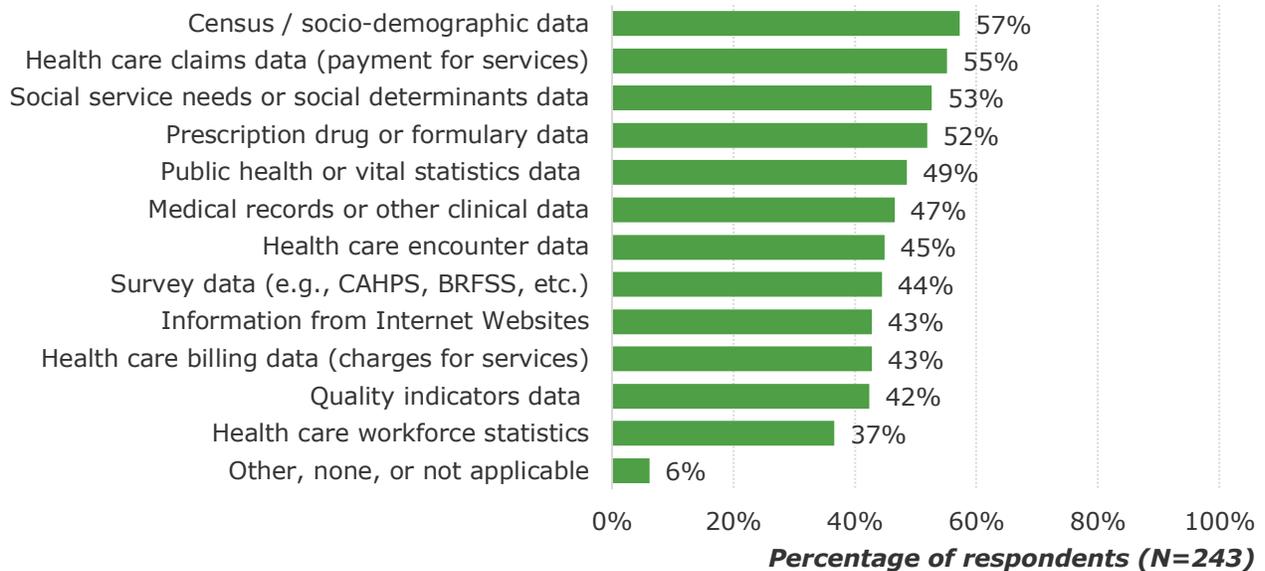
Notes: All categories include related trade or industry associations. Health information organizations includes health information exchange (HIE). Respondents who didn't answer were attributed to a category based on invitation email address; "other" responses were recoded to appropriate categories.

A1.2. How do you use health information?



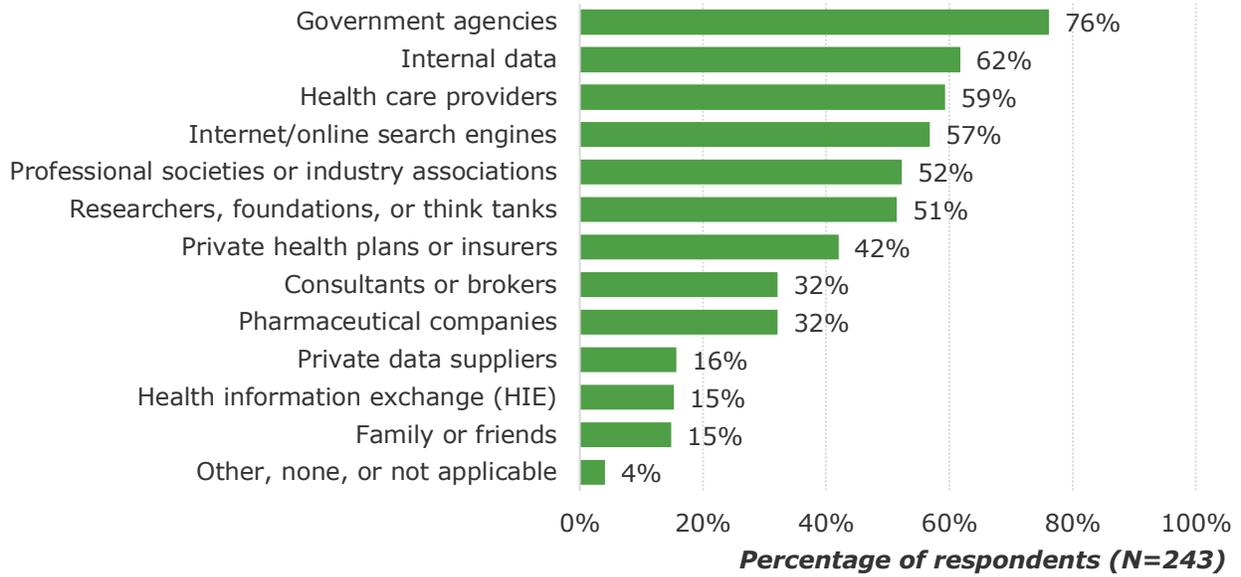
Note: Respondents could choose multiple answers

A1.3. What kinds of health information do you use?



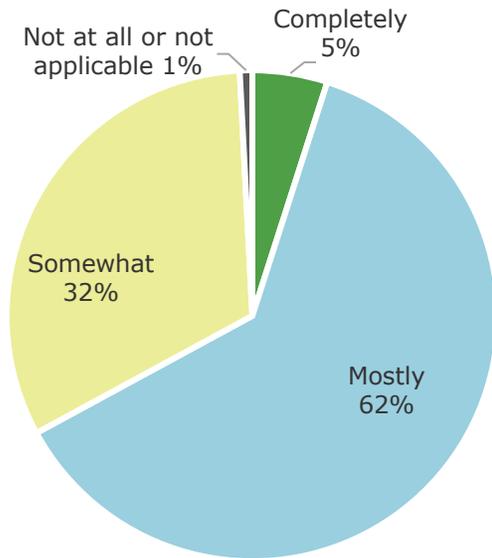
Note: Respondents could choose multiple answers

A1.4. What are the sources of the health information you use?



Note: Respondents could choose multiple answers

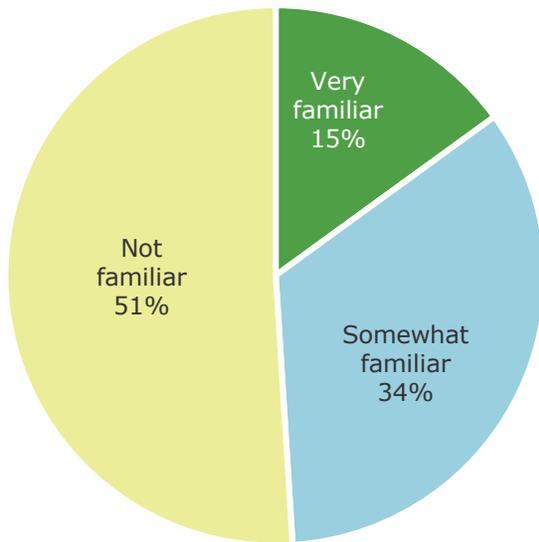
A1.5. How well do your current sources of health information meet your needs?



Stakeholder subgroup	Information needs somewhat or not at all met
Community organization	58% (+)
Government agency	50% (+)
Academic/Researcher	41% (+)
Employer-Purchaser	30%
Consultant/Broker/Vendor	30%
Hospital/Health System	23% (-)
Other Healthcare Facility	22% (-)
Practicing Clinician	22% (-)
Consumer/Patient	20% (-)
Health Plan/Insurer	11% (-)

Note: The pie chart shows percentages of all respondents (N=243). The table shows whether the percentage for a stakeholder subgroup is significantly higher or lower (+/- 0.5 standard deviation) than the average of stakeholder groups (excluding legislators).

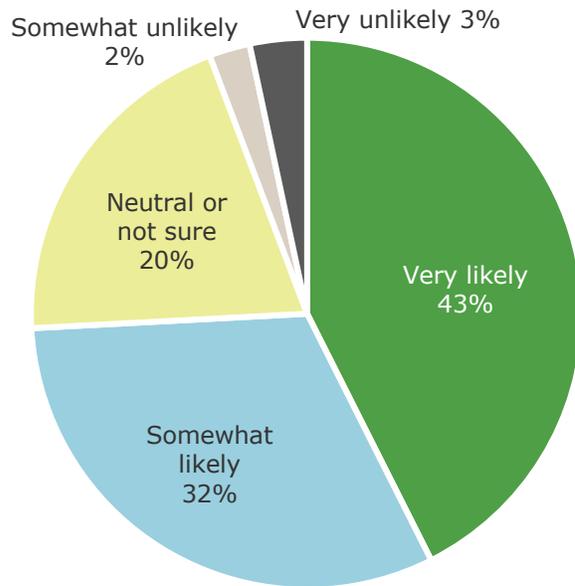
A1.6. How familiar are you with the concept of an all-payer claims database (APCD)?



Stakeholder subgroup	Very or somewhat familiar with APCDs
Hospital/Health System	67% (+)
Consultant/Broker/Vendor	67% (+)
Academic/Researcher	57% (+)
Health Plan/Insurer	56% (+)
Employer-Purchaser	53%
Community organization	50%
Practicing Clinician	39%
Other Healthcare Facility	33% (-)
Consumer/Patient	27% (-)
Government Agency	20% (-)

Note: The pie chart shows percentages of all respondents (N=243). The table shows whether the percentage for a stakeholder subgroup is significantly higher or lower (+/- 0.5 standard deviation) than the average of stakeholder groups (excluding legislators).

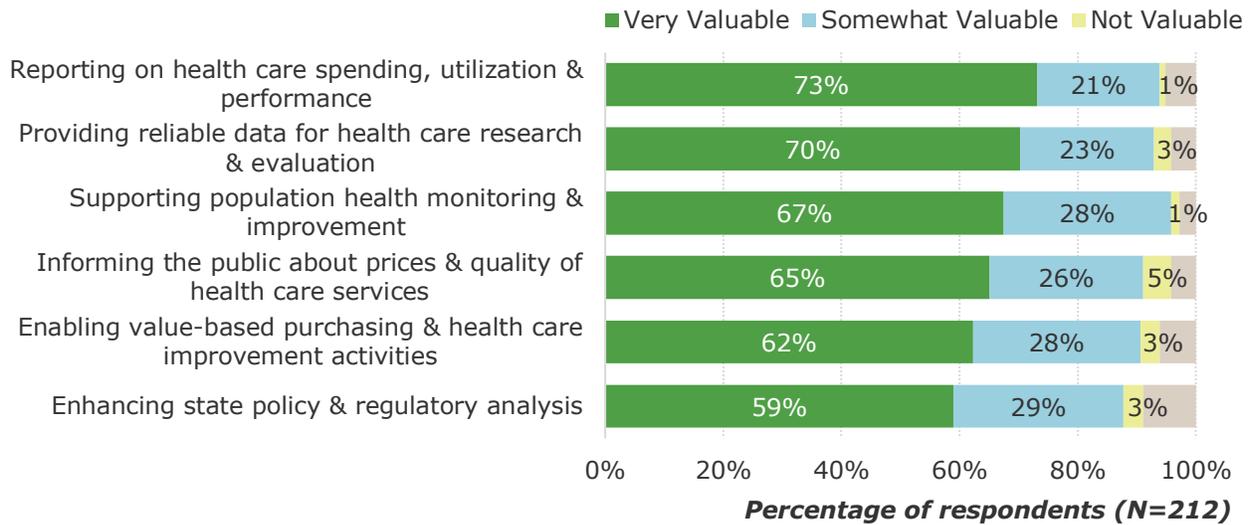
A1.7. How likely are you to use or request data or reports from an all-payer claims database?



Stakeholder subgroup	Very or somewhat likely to use APCD data
Academic/Researcher	90% (+)
Hospital/Health System	81% (+)
Practicing Clinician	80% (+)
Government Agency	79% (+)
Other Healthcare Facility	76%
Employer-Purchaser	74%
Community organization	73%
Consultant/Broker/Vendor	67%
Health Plan/Insurer	56% (-)
Consumer/Patient	47% (-)

Note: The pie chart shows percentages of all respondents (N=209). The table shows whether the percentage for a stakeholder subgroup is significantly higher or lower (+/- 0.5 standard deviation) than the average of stakeholder groups (excluding legislators).

A1.8. Listed below are common uses of an APCD and related data. Indicate how valuable you believe each would be for Missouri.



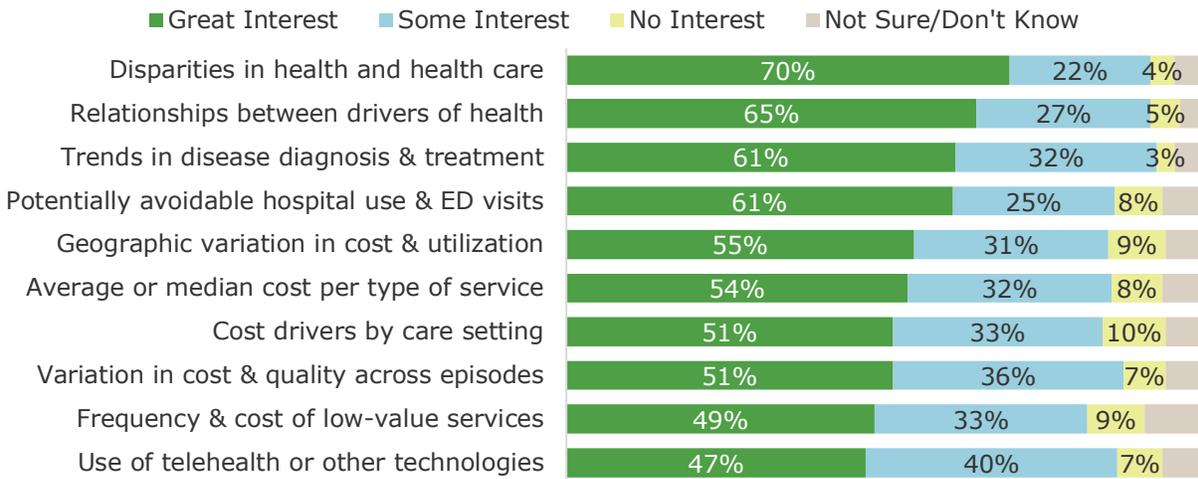
Note: "Not Sure/Don't Know" responses shown in gray. "Other" category not shown.

A1.9. Use Case Rated Very Valuable: By Stakeholder Group

Stakeholder Subgroup	Reporting on Performance	Research & Evaluation	Population Health	Prices & Quality	Purchasing & Improvement	Policy & Regulation	Average
Consumer/Patient	73%	60%	67%	87%	67%	80%	72%
Employer-Purchaser	82%	65%	53%	76%	56%	41%	62%
Government Agency	57%	64%	71%	64%	50%	50%	60%
Hospital/Health System	74%	70%	74%	52%	67%	63%	67%
Other Health Care Facility	50%	56%	61%	61%	56%	50%	56%
Practicing Clinician	53%	73%	53%	53%	40%	53%	54%
Health Plan/Insurer	44%	56%	56%	44%	56%	56%	52%
Community Organization	78%	83%	70%	57%	70%	61%	70%
Academic/Researcher	80%	90%	83%	63%	67%	80%	77%
Consultant/Broker/Vendor	92%	67%	71%	75%	79%	50%	72%

 = higher percentage rating very valuable. + means significantly higher than average of stakeholder groups.
 = lower percentage rating very valuable. - means significantly lower than average of stakeholder groups.

A1.10. How much interest would you or your organization have in the following kinds of data or reports from an APCD?



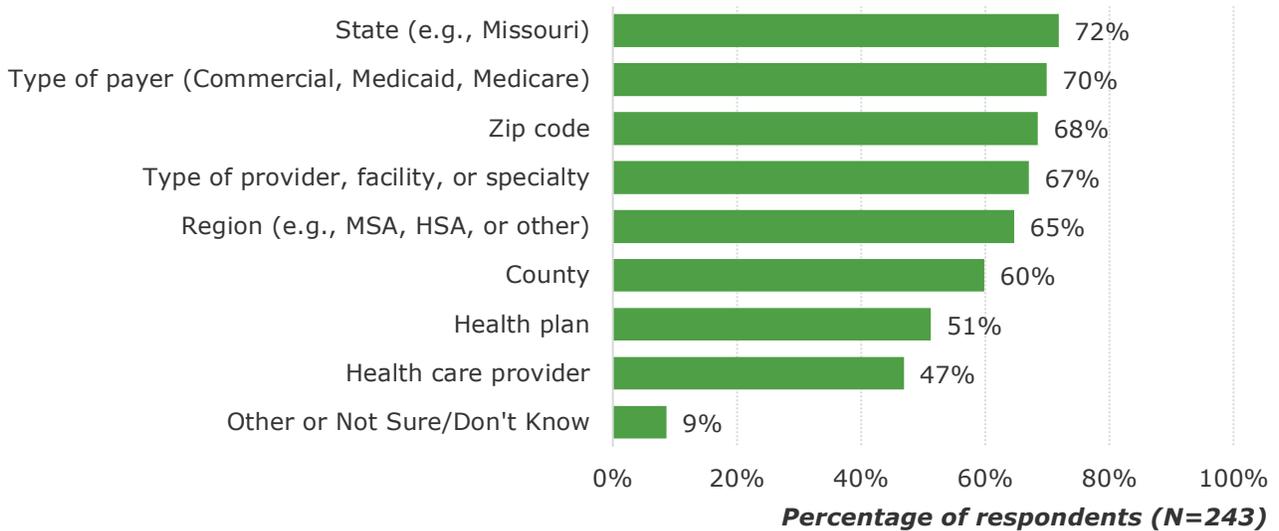
Note: "Other" category not shown. "Not Sure/Don't Know" responses shown in gray.

A1.11. Great Interest in Types of Data/Reports: By Stakeholder Group

Stakeholder Subgroup	Disparities in Care	Drivers of Health	Diseases & Diagnoses	Avoidable Hospital Use	Geographic Variation	Cost Per Service	Cost Drivers	Variation in Episodes	Low-Value Services	Telehealth/Technology	Average
Consumer/Patient	67%	60%	47%	53%	47%	47%	40%	33%	20%	33%	45%
Employer-Purchaser	53%	53%	56%	65%	35%	65%	59%	50%	59%	47%	54%
Government Agency	79%	64%	64%	71%	50%	50%	50%	50%	43%	43%	56%
Hospital/Health System	74%	63%	67%	70%	59%	56%	52%	63%	56%	52%	61%
Other Health Care Facility	72%	67%	56%	50%	56%	56%	56%	44%	44%	56%	56%
Practicing Clinician	53%	53%	60%	47%	53%	47%	47%	53%	40%	47%	50%
Health Plan/Insurer	56%	56%	33%	67%	67%	78%	56%	67%	44%	44%	57%
Community Organization	83%	83%	52%	39%	57%	30%	30%	30%	39%	52%	50%
Academic/Researcher	83%	70%	73%	60%	57%	40%	43%	43%	40%	37%	55%
Consultant/Broker/Vendor	71%	71%	79%	79%	75%	75%	75%	79%	75%	54%	73%

= higher percentage rating very valuable. + means significantly higher than average of stakeholder groups.
 = lower percentage rating very valuable. - means significantly lower than average of stakeholder groups.

A1.12. What level(s) of APCD data or reporting would be most desirable to meet your needs?



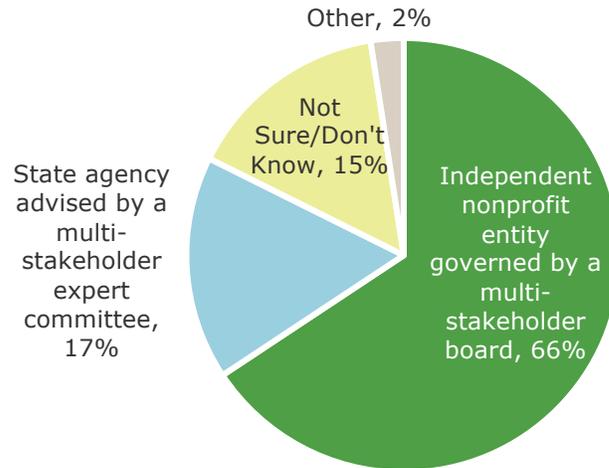
Note: Respondents could choose multiple answers.

A1.13. Interest in Level of Reporting: By Stakeholder Group

Stakeholder Subgroup	State	Region	County	Zip Code	Type of Payer	Type of Provider	Health Plan	Healthcare Provider	Average
Consumer/Patient	93% +	67%	53% -	53% -	73%	53%	40% -	27% -	57% -
Employer-Purchaser	59% -	50% -	35%	44% -	56% -	62% -	62% +	53%	53% -
Government Agency	79%	86% +	93% +	71%	50% -	64%	43% -	29% -	64%
Hospital/Health System	77%	69%	54%	85% +	81% +	65%	62% +	58% +	69% +
Other Health Care Facility	88% +	65%	71% +	76% +	82% +	76% +	35% -	41%	67% +
Practicing Clinician	47% -	47% -	60%	67%	73%	93% +	67% +	53%	63%
Health Plan/Insurer	67%	56% -	56%	44% -	78% +	78% +	56%	78% +	64%
Community Organization	64% -	55% -	77% +	86% +	77% +	55% -	36% -	45%	62%
Academic/Researcher	80% +	77% +	73% +	87% +	80% +	67%	43% -	43%	69% +
Consultant/Broker/Vendor	67%	79% +	46% -	58% -	58% -	75% +	67% +	50%	63%

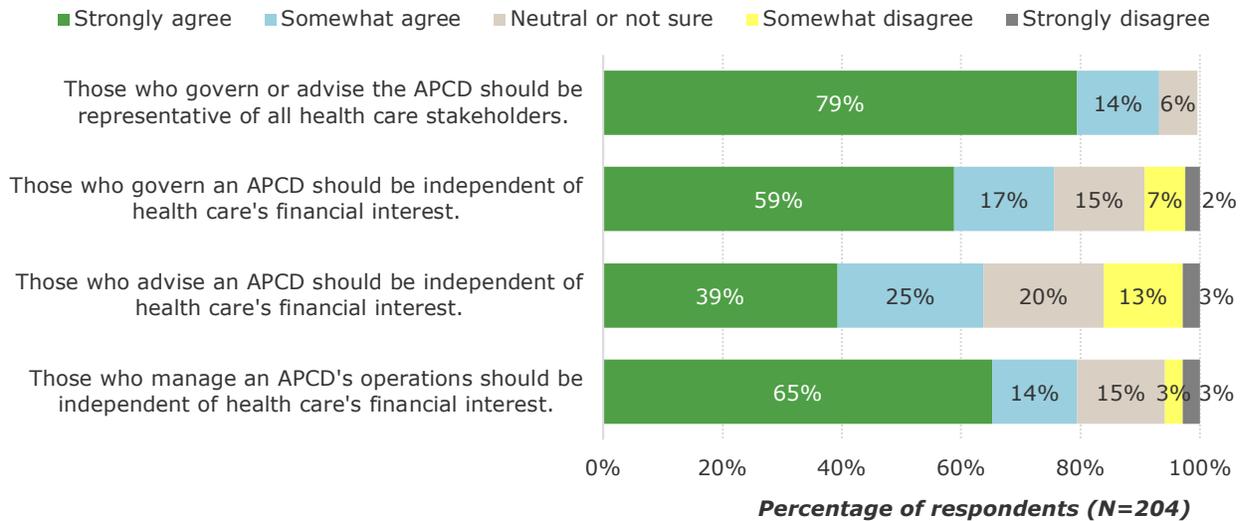
= higher percentage rating very valuable. + means significantly higher than average of stakeholder groups.
 = lower percentage rating very valuable. - means significantly lower than average of stakeholder groups.

A1.14. What kind of organization or arrangement do you believe would be best suited to operate a statewide APCD in Missouri?

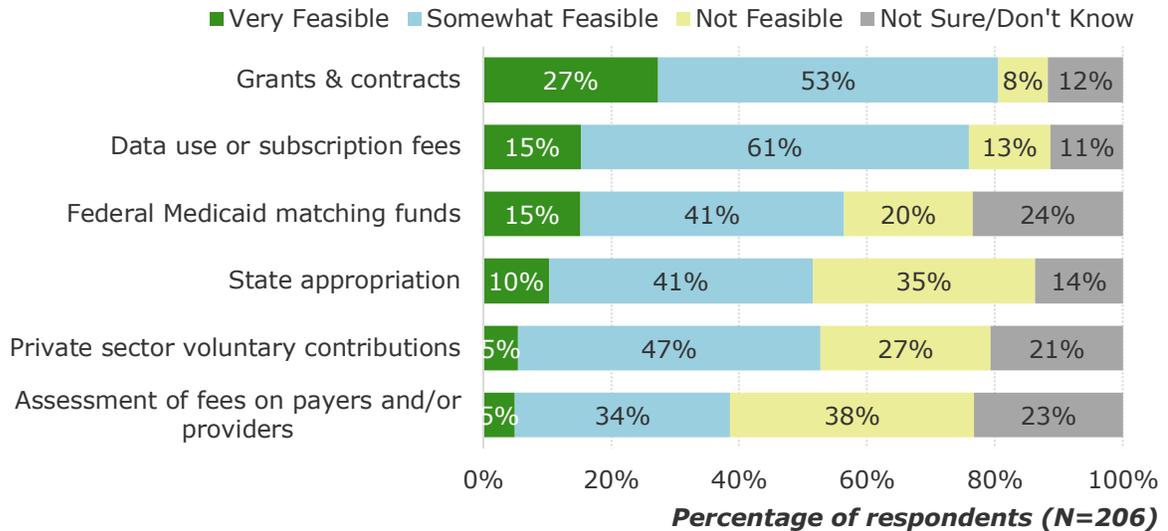


Note: The pie chart shows percentages of all respondents (n=204).

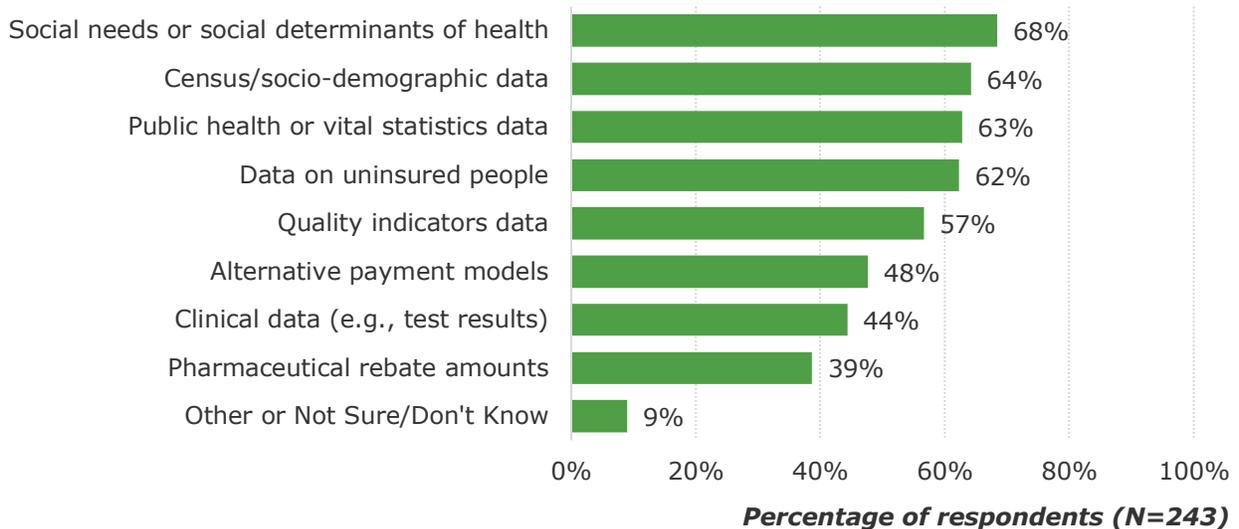
A1.15. Please indicate your response to the following statements: If there is a decision to establish an APCD in Missouri...



A1.16. Listed below are several ways that other states fund their APCDs. Please rate the feasibility of each funding source for Missouri.



A1.17. Are there other kinds of information that you would like to see included in or linked to a health information infrastructure for MO?



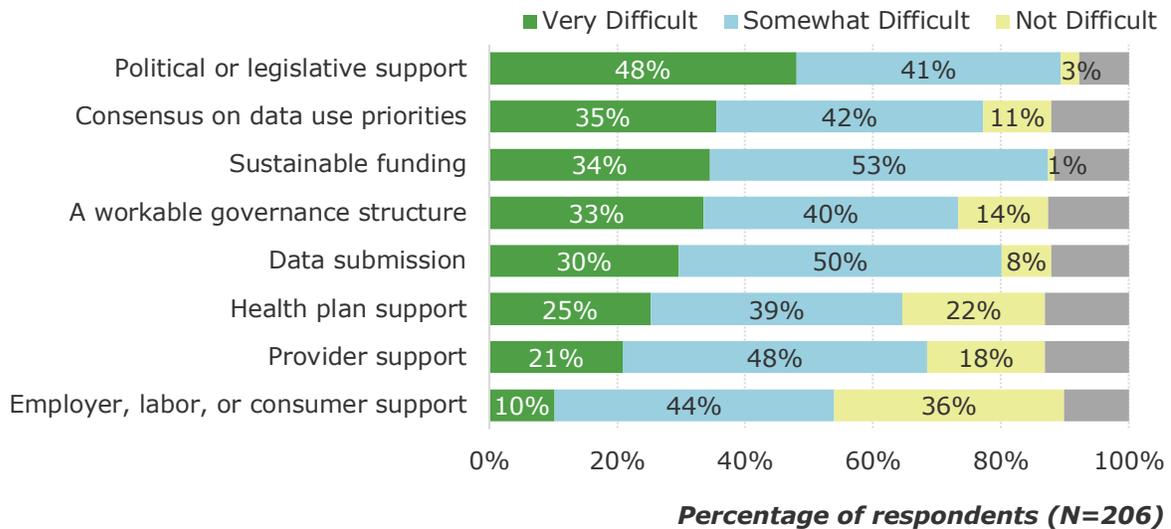
Note: Respondents could choose multiple answers.

A1.18. Interest in Non-Claims Data Linkages: By Stakeholder Group

Stakeholder Subgroup	Social Needs	Census/SES	Public Health	Uninsured	Quality Indicators	Payment Models	Clinical Data	Pharma Rebates	Average
Consumer/Patient	80% +	60%	60%	67%	67% +	40%	27% -	27% -	53%
Employer-Purchaser	32% -	56%	47% -	32% -	47% -	50%	35% -	68% +	46% -
Government Agency	64%	79% +	79% +	71% +	57%	29% -	36% -	21% -	54%
Hospital/Health System	89% +	78% +	81% +	74% +	70% +	70% +	59% +	33%	69% +
Other Health Care Facility	78%	39% -	50% -	72% +	39% -	56% +	50%	44%	53%
Practicing Clinician	40% -	47% -	60%	47% -	40% -	60% +	67% +	47% +	51% -
Health Plan/Insurer	67%	44% -	44% -	56%	44% -	44%	56% +	44%	50% -
Community Organization	91% +	78% +	78% +	87% +	61%	30% -	17% -	9% -	57%
Academic/Researcher	80% +	80% +	77% +	73% +	63% +	30% -	60% +	27% -	61% +
Consultant/Broker/Vendor	63%	58%	42% -	46% -	71% +	63% +	46%	58% +	56%

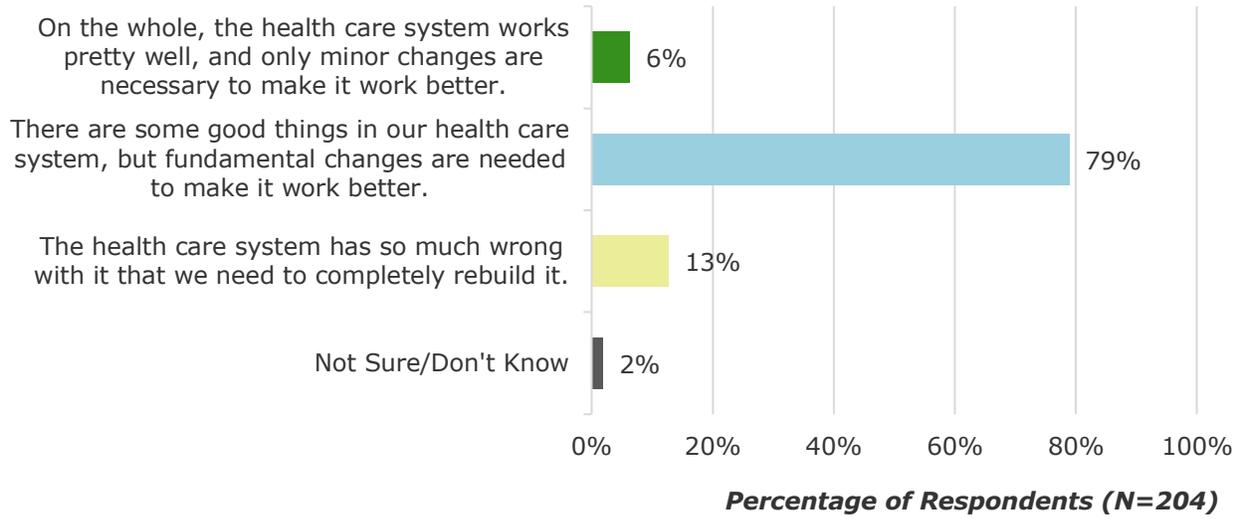
= higher percentage rating very valuable. + means significantly higher than average of stakeholder groups.
 = lower percentage rating very valuable. - means significantly lower than average of stakeholder groups.

A1.19. If there is a decision to establish an APCD in Missouri, how difficult do you believe it would be to achieve each of the following?



Note: "Not Sure/Don't Know" responses shown in gray.

A1.20. Which of the following statements comes closest to expressing your overall view of the health care system?



APPENDIX 2: Interview Research Findings

Methods

We conducted semi-structured interviews with more than 70 health system leaders, practitioners, and advocates identified by MHI to garner deeper insights about current health information uses, needs, and assets, as well as perceptions of the value of an APCD and how it might be used. Most interviews were conducted on an individual basis; some were conducted in a group format. We synthesized responses for each stakeholder group and then synthesized stakeholder group findings into overall findings summarized below for each of the APCD development framework domains. Participants were promised that they would not be individually identified in the findings.

Stakeholder Engagement

How do you use and why do you need health information?

Stakeholders in Missouri identified a broad range of needs for health information to allow for such things as:

- Turning data into information for clinical and nonclinical decision making.
- Measuring internal performance to manage cost and utilization.
- Benchmarking peer performance to identify opportunities for improvement.
- Identifying populations in need of care management.
- Helping consumers/employees understand and navigate their care options.
- Identifying gaps in access to care and advocating for solutions.
- Conducting research and evaluation to identify what works and what doesn't.
- Telling stories with data to bring about positive change.

What are your biggest pain points or unmet needs for health information?

Many unmet needs for information reported by Missouri stakeholders could be addressed by an appropriately resourced APCD, such as:

Lack of timely, unbiased, actionable data that represents all care settings and is granular enough for decision making by stakeholders at various levels.

Lack of information sharing to support program planning and design, care management, research, and evaluation.

Need for agreed-upon standards and metrics to facilitate efficient data sharing and consistent measurement.

Analytic resources and capability to combine and analyze disparate sources of data including claims and clinical data.

Do you think it would be worthwhile for Missouri to create a statewide APCD?

Interviewees expressed support for developing a statewide APCD in Missouri as one step in the larger process of creating a robust health information infrastructure and a learning health system that:

- **Advances the common good** by promoting equitable access to care, improving population health, and ensuring efficient operation of publicly funded programs such as MO HealthNet.
- **Strengthens the market** by giving purchasers, providers, plans, and patients the information they need to fulfill their roles and make decisions.
- **Promotes economic development** and makes the state attractive to employers by helping control benefit costs and improve health care value.

Several noted that gaining or sustaining broad support for an APCD would depend on demonstrating its value in practical ways.

Governance

If a decision is made to create an APCD for Missouri, how do you think it should be governed and managed?

Most stakeholders favored a **public-private partnership** as the most feasible approach for Missouri and to ensure resources and talent to manage the effort. There was a concern about the potential complexity of governing a quasi-governmental entity.

Some advocated for a **public agency** to ensure that governance is accountable to the public interest. They also noted limitations facing state agencies including constrained resources and difficulty attracting skilled staff.

Stakeholders said that **an APCD administrator should be neutral, fair, concerned with equity, transparent, and accountable**. A governance structure should balance stakeholder interests, avoid undue influence by any single group, and ensure the ability to do what's best for the state.

Several urged **the inclusion of end-users on an oversight or advisory body** to ensure the design will meet their needs. The state's MO HealthNet Oversight Committee may offer a model of how to solicit input from interested stakeholders and provide accountability for such an effort.

Should the state mandate submission of claims data by regulated insurers?

(Note: Self-insured employer and union plans governed by federal ERISA law cannot be required to submit data to a state APCD.)

There was wide recognition that realizing the full benefit of an APCD requires comprehensive participation and submission of data by payers.

Some stakeholders said mandating data submission by insurers is the only fair and sure way to ensure equal participation across all payers. They noted that a voluntary approach has achieved only partial participation in the state's health information exchanges (HIEs).

Others said a mandate isn't feasible or desirable and that a voluntary process would facilitate meaningful industry participation. It may be prudent to start with voluntary submission and seek a mandate if a voluntary approach does not lead to desired outcomes. However, a voluntary approach may result in incomplete data if payers are not willing to submit all requested data elements.

There was a concern about fees assessed by third-party administrators (TPAs) for APCD data submission. This practice may discourage voluntary participation by self-insured employers.

Funding

How do you think an APCD could be funded in Missouri?

A diversified funding stream including both public and private sources would help ensure long-term sustainability.

While the private sector and foundations have offered startup support for initiatives such as this in the other states, **some expressed concern about the adequacy and ongoing sustainability of voluntary financing.** There was a concern that data use fees could be a barrier to uptake of the APCD, especially for nonprofit community and consumer advocacy organizations.

Some said a state appropriation was warranted because an APCD would serve a public purpose (for reasons noted above). Federal "pass-through" grants or matching funds would make this more feasible. Precedents for the state's engagement include state funding of the Project ECHO telehealth network, health information exchange infrastructure (with federal "pass through" funds), and public-private economic development ventures.

Technical Build

How would you like to access data from an APCD?

Stakeholders recommended **engaging with users to define key features of usability**. To meet varied needs, three kinds of access were proposed, with appropriate privacy safeguards: (1) reports; (2) interactive query; and (3) data use file. To be usable, data files need to be clean and formatted to be easily uploaded into users’ data systems.

Advocates urged that information should be accessible to people in the community, in a format they can use, and on issues that they care about, including resources to analyze the data and a plain language query tool. Outreach and education would promote uptake on how to access and use the data and how to interpret the information. Users may need support from a data expert to make effective use of data.

In what form should data be collected?

A consumer advocate suggested that it would be prudent to avoid including identifying information in the database to avoid privacy concerns. However, researchers noted that they would need identifiers to link APCD data to other data sources to enable more robust analysis, with safeguards to protect privacy.

A health plan and a researcher proposed a de-identification “hashing” method (similar to what is used in several other state APCD processes) that would remove direct identifiers from the data but allow records to be linked over time without revealing patients’ identities. Hashing could be done by a vendor or tool before the data are submitted to the APCD. MHI’s data vendor currently uses such a methodology.

Health plans urged setting a minimum threshold for payer submission and reasonable timelines for payer compliance. They also noted that if data on alternative payments are collected, there should be a separate process for doing so because such payments are not reconciled at a claims-line level.

Recommended use of definitions, standards, methods, etc.

Use agreed-upon data standards, definitions, or frameworks as they evolve to make claims submission efficient, ensure data linkages are feasible, and pave the way for cross-state data sharing in future. An expert noted some standards (e.g., [HL7](#) and [XML](#)) have been difficult to implement and suggested investigating how to make them workable.

Use common measures of quality and efficiency (e.g., hospital readmissions, avoidable hospital use, Medicare ACO and other measures). Health plans are increasingly adopting [Centers for Medicare and Medicaid Services](#) and National Committee for Quality Assurance [HEDIS](#) measures endorsed by the [National Quality Forum](#) (NQF). The NQF is currently considering a standard for social care measures.

Use open methods so everyone can understand how analyses are done. Adopt a credible risk-adjustment method to promote fair comparisons that account for differences in disease burden and case complexity.

Build on previous efforts to measure total cost of care. Use contractual allowed amount as cost including plan and patient share. Take account of the unique attributes of cost-based reimbursement for critical access hospitals.

Adhere to applicable federal and state privacy laws and regulations (e.g., Health Insurance Portability and Accountability Act (HIPAA) [Privacy Rule](#)). One leader proposed that the entity become certified under a recognized program such as the [HiTrust Common Security Framework](#) as way of demonstrating compliance with security standards.

Are there other kinds or sources of data that you would like to see included in a health information infrastructure for Missouri?

[Race/Ethnicity/Language/Disability](#) (RELD): Stakeholders urged the inclusion of RELD data to assess and improve health equity. However, health plans said they do not systematically collect this data because of legal and liability concerns. APCD data may need to be linked to other data sources to allow for inclusion of RELD. Several suggested electronic health records and/or health information exchanges might be a more consistent source for this data. Providers noted a need to assess the completeness and reliability of their REDL data.

[Social determinants of health](#) (SDOH): Providers reported that screening for health-related social needs is not standardized. While electronic health record standards are evolving to capture social needs, some providers are capturing them through "[Z codes](#)" that can flow to claims data. In addition, claims data are being geocoded to attribute health factors at the ZIP Code and census tract level.

Clinical data: Several stakeholders said the value of an APCD would be enhanced if it were linked to clinical data from electronic health records or health information exchanges. This would enable more robust quality measurement and research using intermediate outcomes such as control of blood sugar and blood pressure, for example. They also noted potential technical challenges of linking an APCD to the four health information exchanges serving Missouri.

Uninsured patients: Advocates noted that claims data do not capture the experience of the uninsured, which could lead to an incomplete understanding of their needs and gaps in care for underserved communities. They proposed this data be incorporated from hospital encounter data collected by the Missouri Hospital Association's [Hospital Industry Data Institute](#) and from federally qualified health centers that participate in a [Missouri Primary Care Association](#) database.

Other data: Other kinds of data that were mentioned as offering value when linked with claims data included:

- Benefit plan design to understand its relation to service use.
- Insurance premium data to calculate medical-loss ratios.
- Survey data on patient-reported outcomes.
- Social service program participation and its relationship to health care use.

Cross-Cutting Issues

Do you have any concerns about Missouri establishing an APCD based on your interests or needs?

Getting caught up in collecting data rather than focusing on the purposes for doing so.

Alienating stakeholders if data are used to take a “gotcha” approach.

Focusing solely on costs could harm access in underserved or rural areas.

Failing to consider the unique attributes of different providers and markets.

Expecting too much from claims data alone (*e.g.*, lag time and missing data elements limit what is feasible).

Promising to do too much too fast (time required for implementation).

What do you foresee as the biggest challenges to creating an APCD in Missouri?

Concerns about data privacy and security could derail data collection.

Getting buy-in and agreement of stakeholders on how data will be used.

Effort required to ensure data quality and completeness.

Uncertainty about the legislature’s potential interest and role.

Financial sustainability if state and/or federal funding is not available.

Feasibility of integrating an APCD into a larger data infrastructure.

APPENDIX 3: State Research Highlights

State Examples: Stakeholder Engagement

This table highlights how stakeholders engaged in creating APCDs in selected states.

State	Impetus for APCD Creation
Arkansas	An ACPD was a key component of the Arkansas Transparency Initiative Act of 2015 enacted by the state legislature with conceptual support from health policy experts at the Arkansas Center for Health Improvement , which is affiliated with the University of Arkansas for Medical Sciences.
Colorado	A bipartisan blue-ribbon commission comprised of diverse health care stakeholders recommended the creation of an APCD through a public-private partnership. This led to the creation of the nonprofit Center for Improving Value in Health Care to administer the APCD.
Massachusetts	A package of reforms championed by the governor and legislature created a Center for Health Information and Analysis and an APCD to support the work of a Health Policy Commission, which oversees efforts to monitor and control the growth of health care spending in the state.
Oregon	Legislation established an APCD to support health care transformation efforts under the auspices of the Oregon Health Authority .
Virginia	A governor’s health reform initiative led to legislation establishing an APCD in partnership with industry associations and the nonprofit organization, Virginia Health Information , under state oversight.
Washington State	The Washington Health Alliance , a coalition of employers, providers, and patients, created a multi-payer claims database to support smart purchasing and accountability. The state subsequently enacted legislation to create an enhanced APCD with the intent that the two databases could be joined, but this goal has not yet been achieved.
Wisconsin	Industry leaders in partnership with state agencies created the Wisconsin Health Information Organization , which operates a statewide APCD on a voluntary basis to support performance measurement and improvement activities by health systems. This effort also fulfilled a legislative requirement for the state to establish an APCD.

State Examples: Use Cases

States typically require that uses of their APCD will benefit residents of the state, as well as meeting other objectives. Some states attend to a full range of use cases while others give priority to a subset of specific use cases based on their mission and resources. Examples that may be relevant to Missouri are highlighted below. *For more examples, see the [APCD Showcase](#) sponsored by the APCD Council and [State APCD Profiles](#) published by the Commonwealth Fund.*

State	Example Uses of an APCD
Arkansas	<p>Preventing rural hospital closures: Assesses outmigration of services from rural counties to show the opportunity for offering services locally.</p> <p>Health care spending for jailed population with serious mental illness: Estimate of savings for treatment at crisis stabilization units.</p> <p>Trends in average cost of prescription drugs: A 68% increase in the cost of EpiPen over two years for commercially insured patients.</p> <p>Geographic variations in opioid drug use and treated prevalence of chronic diseases by county.</p>
Colorado	<p>Shop for care: Consumers can search for average prices paid and quality of care at specific facilities for common procedures and imaging tests.</p> <p>Reference-based pricing: Shows what private insurers pay hospitals for inpatient and outpatient services as a percent of Medicare payment.</p> <p>Trends in telehealth and in-person service use before and during the COVID-19 pandemic.</p> <p>Populations at risk for serious illness from COVID-19: Helped officials and communities plan for the potential impact of the pandemic.</p>
Virginia	<p>Healthcare price transparency: Statewide and regional median prices for 37 services or procedures by place of service and type of provider.</p> <p>Low-value services: Prevalence and cost of low-value services, statewide and by region, that may provide little or no clinical benefit.</p> <p>Potentially avoidable emergency visits by county, region, and insurance type over multiple years.</p>
Wisconsin	<p>Intelligence bank: Hospitals and health system subscribers can benchmark the quality and efficiency of health care providers to identify opportunities for improving health system performance and market agility (prices are normalized to conceal negotiated fee schedules).</p>

State Examples: Technical Build

Several states are starting to make advanced use of data from multiple sources.

State	Approach to Advanced Data Collection & Use
<p>Arkansas</p>	<p>Linking claims data to a registry of medical marijuana dispensing to allow research on its health effects.</p>
<p>Colorado</p>	<p>Collecting information on value-based payments and pharmaceutical rebates to support the state’s primary care and affordability initiatives.</p> <p>Geocoding the APCD with demographic and socioeconomic data from the U.S. Census Bureau to address health equity by allowing more robust analyses of disparities at the ZIP Code and census block levels.</p>
<p>Massachusetts</p>	<p>Collecting aggregate health plan spending data including value-based payments to track trends in statewide health care expenditures overall and by type of insurance product (e.g., HMO, PPO) and type of service (e.g., inpatient, outpatient, professional services, and pharmacy).</p> <p>Requiring health plans to include both census block and ZIP Code in demographic files to allow analyses of disparities in access to care and use of resources at a community and neighborhood level.</p> <p>Creating a master index so that data on race and ethnicity included in the state’s hospital encounter database can be linked to claims data in the APCD for analysis of disparities across care settings.</p>
<p>Oregon</p>	<p>Recent legislation requires state-regulated insurers and Medicaid coordinated care organizations to collect and report information on enrollees’ race, ethnicity, primary language, and self-reported disability status (RELD) at a more granular level than current federal standards.</p> <p>Analyzing diagnostic “Z codes” that describe social needs, as reported by providers in claims data, to assess the prevalence of reported health-related social needs such as homelessness. The reporting of such codes by Medicaid coordinated care organizations is expected to increase as they receive incentives for addressing social needs.</p>

APPENDIX 4: Components of an APCD Analytic Plan

OBJECTIVE	CONSIDERATIONS
<p>Establish a process for continuous data quality assessment, improvement, and validation</p>	<p>What is the plan to assess data quality and how to address issues that are identified?</p> <p>How will the downstream implications of data quality issues be handled?</p> <p>Is there a plan to provide carrier feedback and improvement targets?</p> <p>Is there a review and validation period prior to the release of public reports?</p>
<p>Document the dissemination plan that balances privacy protections with data utility</p>	<p>What is the data oversight process and how will release policies be established and conducted?</p> <p>Will there be data use agreements for some data sets? Which?</p> <p>Is there a plan for disseminating APCD data, reports?</p> <p>Is the process for requesting and obtaining data transparent and equitable to different users (e.g., public, researchers)?</p> <p>What statistical modifications will be implemented to mask identifiable data?</p> <p>Is there a review and validation period prior to the release of public reports?</p>
<p>Document policies and process for data collection, analytics, and release that are consistent with APCD governance structure</p>	<p>Are there restrictions to uses and access?</p> <p>Are there rules or mandates about who can access the data?</p> <p>Will access to APCD data be permitted, and to whom and under what conditions?</p> <p>Does the law mandate certain reports or applications (consumer websites)?</p> <p>Are data release fees established; if not, how will they be set?</p>
<p>Define the stakeholder engagement process for all stages of the analytic process</p>	<p>How will stakeholder input be assured initially and on an ongoing basis?</p> <p>How will individual stakeholder views be managed?</p> <p>What process will be used to manage disagreements or concerns?</p> <p>Will there be technical advisory groups for various aspects of the data collection, analytic, release cycle?</p>

Excerpted from: ALL-PAYER CLAIMS DATABASE DEVELOPMENT MANUAL, University of New Hampshire and the National Association of Health Data Organizations, March 2015, Table 7, page 66.

APPENDIX 5: Missouri's Health Data Assets and Profiles of Missouri Health Information Organizations

This Appendix profiles several of Missouri's existing health data assets and analytic capabilities, which can contribute to a statewide health information infrastructure. The table below summarizes key strengths of these assets that an APCD can build upon, gaps in data that an APCD could address, and technical challenges to be solved when integrating a statewide APCD into a functional health information infrastructure.

The following organizations are profiled:

Health Information Exchange Organizations

- Lewis and Clark Information Exchange (LACIE)
- Midwest Health Connection (MHC), a subsidiary of Velatura HIE Organization
- Show-Me Health Information Network of Missouri (SHINE)
- TIGER Institute Health Alliance (affiliated with the University of Missouri)

Academic, Industry, and Research Organizations

- Health Industry Data Institute (HIDI)
- Midwest Health Initiative (MHI)
- Missouri Primary Care Association (MO-PCA)
- Quality and Value Innovation Consortium (QVIC)
- University of Missouri Center for Health Policy (CHP)
- Washington University Institute for Public Health (IPH)

"By identifying areas of common interests, you can create situations where people overcome natural antagonism and see opportunity to work together."
-Missouri Academic Leader

Missouri’s Health Data Assets

Missouri’s Health Data Assets	Gaps to be Addressed
CLAIMS DATA	
<p>In cooperation with purchasers and health plans, the Midwest Health Initiative (MHI) maintains the largest commercial claims database for Missouri and bordering metro areas, representing care received by 2.2 million people covered by union- and employer-sponsored health plans. Data are used to understand health and chronic condition prevalence, analyze and improve the quality, affordability, and experience of care. Working collaboratively, MHI and other stakeholders have joined together to improve health and care quality.</p> <p>MHI has been designated a Qualified Entity by the federal government so that it can include claims data for enrollees in the federal Medicare program.</p>	<p>MHI’s database does not include claims data on the care of low-income Missourians enrolled in MO HealthNet, the state’s Medicaid program.</p> <p>Including Medicaid claims data in an APCD would be valuable because low-income people may be dually eligible for Medicaid and Medicare and often change enrollment between Medicaid and private coverage.</p>
<p>The Center for Health Policy in the University of Missouri Medical School, in collaboration with the University’s Office of Social and Economic Data Analysis, provides ongoing research and analysis on the MO HealthNet program under contract with the Missouri Department of Social Services.</p> <p>Analyses have linked Medicaid claims with data from other sources such as electronic health records, the Supplemental Nutrition Assistance Program, a cancer registry, and birth and death records.</p>	<p>Combining Medicaid claims with commercial and Medicare claims in an APCD would enable enhanced analyses to support the state’s Medicaid transformation agenda.</p> <p>Expansion of Medicaid in Missouri means that many formerly uninsured Missourians will be represented in Medicaid claims data, making the data even more useful.</p>
CLINICAL DATA	
<p>Missouri health systems and medical groups engaged in value-based care arrangements are linking clinical data from their electronic health records with claims data from payers to help manage the cost and quality of care for population health management, quality improvement, and bundled care initiatives.</p>	<p>Providers typically lack comprehensive claims data on their entire patient panels and populations, a gap that an APCD might help to address to create a “single source of truth” for measuring performance and facilitate the transition to value-base care.</p>

<p>A growing number of Missouri’s health care providers participate in one of four health information exchanges (HIEs) serving the state:</p> <p>Lewis & Clark Information Exchange, which uses the Tiger Institute’s technology platform</p> <p>Midwest Health Connection, part of Velatura HIE Organization</p> <p>SHINE of Missouri, affiliated with the Missouri State Medical Association</p> <p>Tiger Institute Health Alliance, a division of the University of Missouri’s Tiger Institute for Health Innovation.</p> <p>Data use agreements allow authorized HIE participants to share and use clinical information for treatment purposes. Some may also permit use of data for payment, health care operations, clinical trials participation, and research approved by an institutional review board. All four HIEs have data use agreements and capability to share data with each other and with HIEs outside the state when Missouri patients cross state lines for care.</p>	<p>Linking clinical data from an HIE with claims data in an APCD would allow more robust analyses of health care access, quality, and outcomes. Current data governance typically does not envision such linkages.</p> <p>Stakeholders and participants in HIEs and an APCD would need to approve this purpose and amend data use agreements so that clinical and claims data could be linked while protecting patient privacy.</p> <p>Some stakeholders expressed concern that linking claims with clinical data from several HIEs serving Missouri may present a challenge. A commenter noted that the challenge would be more relational than technical in nature. Partnering initially with one of the state’s HIEs may be prudent to establish a data-linking proof of concept.</p>
<p>HOSPITAL AND PRIMARY CARE ENCOUNTER DATA</p>	
<p>The Missouri Hospital Association’s Hospital Industry Data Institute (HIDI) offers data collection, aggregation, and analytic services and tools to help health care providers, state hospital associations, and state data agencies better understand health care utilization, service patterns, risk factor contribution, and clinical and financial performance.</p> <p>HIDI performs state-mandated public health reporting on behalf of Missouri hospitals and collects and submits hospital encounter data for 15 states (including Missouri) that participate in the federal Health Care Cost and Utilization Project.</p>	<p>Linking hospital encounter data to an APCD can fill gaps in information, such as more complete diagnostic codes and demographic data, but would require obtaining legal permissions from payers and developing technical methods for matching records across databases while protecting patient privacy.</p>

<p>The Missouri Primary Care Association maintains a Population Health System that aggregates encounter data from 28 federally qualified health centers (FQHCs) serving more than 500,000 Missourians at 200 locations statewide. The association also aggregates data on health-related social needs, which FQHCs collect using a standard screening tool built into their electronic health records. These data used for federal reporting, benchmarking, and quality improvement purposes.</p>	<p>Linking FQHC encounter data with hospital encounter data for uninsured patients would offer a more complete picture of health care access and utilization patterns to identify gaps in care and opportunities for meeting the needs of underserved communities.</p> <p>Doing so would require permission from participating FQHCs and developing a technical method for linking records while protecting patient privacy.</p>
<p>PUBLIC HEALTH DATA</p>	
<p>The Missouri Department of Health and Senior Services (DHSS) maintains vital statistics on births and deaths in the state as well as other public health data.</p> <p>The Missouri Public Health Information Management System (MOPHIMS) provides a common means for users to access public health related data to assist in defining the health status and needs of Missourians.</p> <p>The Missouri Cancer Registry and Research Center, a collaboration between DHSS and the University of Missouri, maintains the state’s mandated central cancer registry.</p>	<p>Linking public health data to a state APCD can enhance research on health outcomes and monitoring of population health trends.</p> <p>Stakeholders report that the state’s public health data systems are antiquated and slow to provide information to decision makers and the public. The state is planning to use federal pandemic relief funding to upgrade its public health data systems.</p>
<p>RESEARCH DATA</p>	
<p>The Quality and Value Innovation Consortium (QVIC), part of Institute for Innovation and Quality at the University of Missouri-Kansas City, has convened a group of Kansas City area stakeholders to improve the value of health care through regional collaboration.</p> <p>QVIC engages in three activities: 1) regional quality improvement projects using hospital encounter data; 2) training and education to implement change; and 3) community dissemination and engagement.</p>	<p>The QVIC is currently limited to hospital-based data. Use of data from a statewide APCD would allow QVIC to expand its focus outside hospitals and provide one data source for multiple initiatives.</p> <p>Curated APCD data would also enhance the validity and integrity of the QVIC’s research by enabling more complete outcomes assessment across care systems.</p>

REVISED AFTER PUBLIC COMMENT

<p>Washington University's Institute for Public Health conducts research and analysis to promote sound policy decisions and engages in community partnerships to address complex health issues and health disparities facing the St. Louis region. Faculty engage with public health leaders and use multiple data sources to support their work.</p> <p>The Institute's researchers collaborate with the St. Louis Integrated Health Network of hospitals, community health centers, and other safety-net providers to encourage an evidence-based, regional approach to local health care delivery that offers access to high-quality, affordable healthcare for all residents of Metropolitan St. Louis.</p>	<p>Institute faculty have used Medicaid and Medicare claims data for specific projects. They see value in bringing these data together longitudinally with commercial claims data for ongoing projects.</p> <p>Researchers have sought, but not been granted, access to clinical data from HIEs to examine care patterns regionally (e.g., how the COVID-19 pandemic affected care seeking for heart conditions).</p>
---	---

Lewis & Clark Information Exchange

Purpose: The mission of the [Lewis & Clark Information Exchange](#) (LACIE) is “to improve the health and economic status of those we serve by facilitating clinical data sharing across various medical trading areas to include the state of Missouri, and delivering common capability that citizens, providers, and institutions are able to use. LACIE seeks to enhance patient safety by eliminating obsolete, paper-based medical records and combining patient data into a single, widely available digital record.”

Formation: In 2008, Heartland Health—now [Mosaic Life Care](#)—created a health information network to encourage clinical data sharing with stakeholders in its Medicare [accountable care organization](#) (ACO). The first exchange of data occurred in September 2010. LACIE became an independent nonprofit organization in 2013 to encourage greater participation by entities not affiliated with the ACO.

Governance and Operations: The organization is governed by a board of directors comprised of member hospitals, providers, large employers, consumer advocates, and federally qualified health centers. Most major participants in LACIE have a seat on its board, which sets policy for data governance and operations. LACIE employs two staff and outsources all technical support.

Participants and Service Area: Approximately 80 percent of LACIE’s 95 organizational participants are based in Missouri, primarily in the greater Kansas City region. LACIE is one of four HIEs serving Missouri and one of four serving Kansas.

Data Uses: LACIE transmits clinical data from participants’ electronic health records (EHR) systems. Data use agreements generally specify that LACIE may be used only for treatment purposes; additional uses for health care payment and operations may be permitted when specified. LACIE has received requests to use HIE data for research purposes; to date, the organization’s board of directors has not granted such requests.

Infrastructure: LACIE is a [query-based exchange](#). The [TIGER Institute](#), which operates a separate HIE serving Missouri, is LACIE’s technology provider. Through this [affiliation](#), providers can make a single connection to both HIEs and patients can make a single request to opt-out of both HIEs. Security filters ensure that only authorized participants view information. A connection to the nationwide [eHealth Exchange](#) allows data sharing when patients visit providers outside Missouri and Kansas.

Funding: LACIE’s \$1.2 million annual budget is primarily funded through subscription fees paid by members. Heartland Health invested approximately \$2 million in start-up funding for the HIE. LACIE has received approximately \$1.7 million through Kansas grant programs and \$5.6M through the MO HealthNet [HIE Onboarding Program](#), which aims to increase participation by providers serving Medicaid. This program has resulted in approximately 65 new participants in LACIE, 47 of which are long-term care/skilled nursing facilities.

Future Plans: The organization’s leaders welcome the opportunity for health care payers to participate in the HIE to support care coordination and facilitate pre-authorization of services.

Midwest Health Connection, a subsidiary of Velatura

Purpose: [Midwest Health Connection](#) (MHC) is a statewide health information exchange (HIE) network that ensures patients, providers, physicians, hospitals, and other health care organizations in Missouri and surrounding states have access to critical medical record information in order to improve patient care and public health. MHC's corporate parent, [Velatura](#), strategically aligns and connects people, organizations, technology, ideas, and information to improve health care, simplify work, and reduce costs.

Formation & Governance: MHC was started by stakeholders in 2009 and became a nonprofit organization in 2011. On January 1, 2021, MHC affiliated with [Velatura HIE Organization](#), which is part of Velatura Public Benefit Corporation. Velatura is headquartered in Michigan and governed by a board of directors.

Participants & Service Area: More than 1,300 health care organizations participate in the Velatura HIE network in the Midwest and across the United States including hospitals, post-acute care facilities, clinics and physician practices, federally qualified health centers, behavioral health facilities, long-term care and skilled nursing facilities, health plans, accountable care and care management organizations. MHC has agreed to share data with the [Kansas Health Information Network](#) when patients cross state lines for care.

Data Uses & Services: HIE services include clinical document exchange, direct secure messaging, alert notifications, public health reporting, patient consent registries (patients must opt-in to have their data included in the HIE), and business continuity planning. The HIE acts as a business associate to covered entities subject to the HIPAA Privacy Rule. Standard data use agreements permit patient data to be collected from providers' electronic health records and shared with HIE participants for treatment, payment, and health care operations purposes. Participants can use data for additional purposes, such as clinical trials participation and research approved by an institutional review board, subject to contract addenda. Patient data include diagnoses, allergies, medications, problem lists, lab results, imaging reports, and immunizations.

Infrastructure: MHC is transitioning its [query-based exchange](#) to a cloud-based centralized [technical architecture](#). It serves as a HIE gateway in the [Patient Centered Data Home](#) initiative, which facilitates the exchange of clinical information by connecting more than 40 HIEs. Connections also include the Veterans Administration and the Department of Defense.

Funding: MHC received \$14 million in startup funding through the federal HITECH Act. It has been financially self-sustaining since 2014 through annual member subscription fees. Lack of ongoing state funding for HIE infrastructure led MHC to affiliate with Velatura to support investments in technical innovation and market expansion.

Future Plans: Velatura aims to become a health data utility offering analytic services for all types of data. For example, the HIE's Enterprise Master Patient Index can support other applications that require accurate patient identification and data linking. Velatura is working to become certified as a source of clinical data for health plan quality measurement.

Show-Me Health Information Network (SHINE)

Purpose: [SHINE of Missouri](#)'s mission is to improve the quality of care and promote patient and population health through a physician-led health information exchange (HIE) that enables secure sharing of health information at the patient, practice, and community levels; to reduce inefficiencies in the delivery of care; and to provide the foundation for new models of health care delivery and reimbursement.

Formation & Governance: SHINE is affiliated with the Missouri State Medical Association and operated by [KONZA National Network](#), headquartered in Topeka, Kansas. KONZA is governed by a board of directors comprised of Kansas health care stakeholders.

Participants & Service Area: SHINE connects more than 1,000 health care providers [across Missouri](#), with the majority located in the greater Kansas City region. SHINE has agreed to share data with the [Kansas Health Information Network](#) (KHIN) when patients cross state lines for care. KONZA provides HIE solutions to health systems, health plans, medical researchers, and state medical societies across the country, including KHIN.

Data Uses & Services: SHINE offers a suite of health information technology tools to help health professionals across the state of Missouri connect, analyze, engage, and transform the health care industry. The network provides secure access to patient data from providers' electronic health records, secure messaging between physicians, enhanced physician to patient communications, and public health reporting and disease registries.

- Providers can use web-based dashboards to risk-stratify their patient panel and manage chronic diseases and hospital readmissions, among other functions.
- Patients can sign up to access information in the HIE from an online patient portal, and can opt-out of having their information included in the HIE using an online form.

Infrastructure: KONZA utilizes a proprietary data architecture that is securely maintained in the Azure cloud to power analytic solutions. KONZA's clinical platform normalizes and compiles data from participants into actionable intelligence. KONZA has been accredited by the [Electronic Healthcare Network Accreditation Commission](#) for compliance with industry standards and HIPAA regulations. KONZA recently earned the Validated Data Stream designation from the [National Committee for Quality Assurance](#), which ensures the accuracy of aggregated clinical data for use in quality reporting programs.

Funding: KONZA was [recently awarded](#) a two-year cooperative agreement under the U.S. Office of the National Coordinator for Health Information Technology's [Star HIE Program](#) to establish COVID-19 public health registries in 10 states, including Missouri, and assist providers to report COVID-19 test results electronically to state public health departments.

Tiger Institute Health Alliance

Purpose: [Tiger Institute Health Alliance](#) (TIHA) is a coalition of health care organizations dedicated to improving the efficiency and quality of care delivery and the health status and clinical outcomes of communities.

Formation & Governance: TIHA is a division of the [Tiger Institute for Health Innovation](#), which was formed in 2009 as a public-private partnership between the University of Missouri and Cerner Corporation. The Institute is overseen by the Board of Governors comprised of key stakeholders representing the University and Cerner. Committees and user groups representing participants of TIHA and the Lewis And Clark Information Exchange (LACIE) provide operational governance for the TIHA Health Information Exchange (HIE).

Participants & Service Area: More than 125 organizations utilize the TIHA HIE across Missouri and Kansas including hospitals, skilled nursing facilities, physician practices, FQHCs, home health agencies, and others. TIHA connects to providers in other states and public health departments, state government, the VA/DoD, and other health information networks in the US. The Hospital Industry Data Institute (HIDI) is a participant and TIHA partners with it to support the Missouri Care Coordination Insights program. It is collaborating with LACIE to consolidate connections to the TIHA HIE platform.

Data Uses & Services: TIHA's HIE provides access to and retrieval of patient information to authorized users, facilitating safe, efficient, effective, and timely patient care. Members have access to aggregated views of care summaries, clinical notes, and other health information to manage patient care. Current permitted uses of data are for HIPAA permitted purposes, individual authorizations, organ donor services, and other authorized purposes. TIHA provides the following services in addition to [query-based exchange](#).

- [Directed exchange](#) that routes clinical data between hospitals, physician practices, labs, pharmacies, registries, and other systems.
- ADT notifications that alert providers and health plan care managers when patients or members are admitted to, discharged from, or transferred between hospitals.
- Data as a Service enables the contribution of data on behalf of participants to support other programs, research, and initiatives they participate in.
- Reporting and analytics.

Infrastructure: Tiger Institute employs open-source code that leverages [Integrating the Healthcare Enterprise](#) standards to connect electronic health record (EHR) systems. The Cerner HIE platform enables the exchange of data between participants and other systems. The Tiger Institute also utilizes Cerner's cloud-based [HealthIntent](#) platform that aggregates clinical, claims, HIE, and other datasets to manage individuals and populations.

Funding: TIHA is primarily funded through participant and health information network subscription and service fees. It is also contracted to provide health information network services to the state of Missouri.

Future Plans: The Tiger Institute is focused on scaling its platforms and leveraging the data in them to advance clinical outcomes, value-based care, research, and cost efficiency across Missouri and beyond.

Hospital Industry Data Institute

Purpose: The [Hospital Industry Data Institute](#) (HIDI) is a nonprofit organization that operates as a convener, data aggregator, and analytics service supplier to clients in Missouri and nationwide. HIDI provides timely access to data and information services that supports research, public health, and industry operational intelligence.

Formation and Governance: Founded in 1985 by the [Missouri Hospital Association](#), HIDI is governed by a [board of directors](#) comprised of executives from Missouri hospitals and health systems. The board meets six times annually to make policy decisions regarding the Institute's direction and focus. The Institute employs 32 staff.

Services: HIDI offers a range of data collection, aggregation, transformation, visualization and analytic services and tools to help its clients better understand health care utilization, service patterns, risk factor contribution, and clinical and financial performance. HIDI's research on the influence of social determinants on health outcomes and federal programs has been recognized nationally and published in several academic journals.

Clients and Service Area: More than 2,000 hospitals and health systems, state hospital associations, and state data agencies across the country use HIDI's data and services. In Missouri, HIDI is the primary collection agent for hospital and ambulatory surgery center discharges and financial data reporting to the state, as well as for hospital service and characteristic data to meet state hospital licensure needs. HIDI-provided data and expertise support, visualization, and analytics to assist the state's COVID-19 pandemic response. Nationally, HIDI collects and submits hospital encounter data for 15 states (including Missouri) that participate in the [Health Care Cost and Utilization Project](#).

Infrastructure and Tools: HIDI uses a modified [Scaled Agile Framework](#) (SAFe) for product development and service delivery. A collaborative technology framework allows HIDI to serve as a neutral convener to build and transform a variety of data assets into valuable insights. Data tools offer functions and features such as: 1) patient cohort and analytic watchlists, encounter notifications, and predictive alerting; 2) curated health-related data for community health needs assessments; and 3) business intelligence and interactive visualization for analyzing market and utilization patterns and quality and financial outcomes and trending. In 2021, HIDI led the development of the [Missouri Care Insights Project](#) in collaboration with the State, hospital providers, the Tiger Institute for Health Innovation, and other Missouri health information networks. The project demonstrated technology and interoperability to capture, aggregate, and integrate electronic health record data to deliver care insights and improve care coordination within the state.

Funding: The Institute is funded through contracts and fees from clients.

Future Plans: HIDI's services evolve to keep pace with the changing health care environment. "We recognize the value of partnering with entities to economize and increase the value of technology investments across our state," says Theresa Roark, HIDI senior vice president. "We are committed to building a shared vision to improve care and actively pursue and build relationships that leverage complementary technology investments."

Midwest Health Initiative

Purpose: The [Midwest Health Initiative](#) (MHI) brings together those who provide, pay for, and use health care to address some of our region’s most pressing health care challenges. Its mission is to provide a forum for trusted information and shared responsibility are used to improve health and the quality and affordability of health care for all. A belief in the power of information and collaboration to transform health care is the common thread that unites MHI leaders. MHI also stewards the largest commercial claims dataset for Missouri and its bordering metro areas.

Formation and Governance: Incorporated as a 501(c)(3) regional health-improvement collaborative organization in 2010, MHI is governed by a multi-stakeholder board of directors representing health plans, health systems, physicians, and purchasers, and the public at large (*e.g.*, labor unions, business, and government entities). The board has a purchaser majority.

Clients or Participants & Service Area: MHI data exists to make health care work better for those who reside in Missouri and its bordering metro areas. Its data represents 2.2 million lives from all 115 Missouri counties, 53 Illinois counties, and 32 Kansas counties. MHI data is provided voluntarily by the region’s major health plans.

Data Uses & Services: MHI stewards a Limited Data Set defined and regulated by federal privacy laws. It integrates enrollment, medical and pharmacy claims, and provider files. The data provides insights into disease prevalence; service utilization and cost; gaps in care, including resource use among subpopulations; adherence to care guidelines; and the impact of improvement efforts, including improvements in affordability and care value. Organizations with a “health care operations, improvement or research purpose” as defined by HIPAA, may access MHI data under a written Data Use Agreement. MHI also shares reports with its partners and the public.

Infrastructure & Tools: [Milliman MedInsight](#), Inc., MHI’s data vendor provides data collection, integration, hosting, and analytical software and support. Through Milliman, MHI utilizes the Optum episode grouper and risk adjuster and other analytical tools, such as Milliman’s [Health Waste Calculator](#). Licensees obtain access to the MHI data and tools.

Funding: MHI realizes revenues of about \$700,000 annually from user fees, grants, and contributions. Additional in-kind contributions are made by the [St. Louis Area Business Health Coalition](#).

Future Plans:

- MHI welcomes the partnership of other stakeholders in socializing this report to identify advocates for a single, trusted, all-payer claims database in Missouri.
- Expand and advance MHI’s dataset to include data from publicly insured programs. MHI is a Centers for Medicare Services (CMS) [Qualified Entity](#) eligible to receive Medicare claims data for use in performance measurement initiatives.
- Working with others, pilot access to race and ethnicity data from enrollment files and linked access to laboratory or other diagnostic service data.

Kansas City Quality and Value Innovation Consortium

Purpose: The [Quality and Value Innovation Consortium](#) (QVIC) is a group of Kansas City area stakeholders committed to improving the quality and value of health care and reducing health inequities through regional collaboration. In practical terms, QVIC seeks to support stakeholders with implementation into practice and to measure the impact of those implementations on outcomes.

Formation & Governance: QVIC was started in 2018 and is now housed within the new Healthcare Institute for Innovations in Quality (HI-IQ) at the [University of Missouri-Kansas City](#) (UMKC), with operational and quality improvement support from health services research staff at [Saint Luke's Health System](#) in Kansas City and partnering academic researchers from UMKC Schools of Pharmacy, Medicine, and Nursing, as well as University of Kansas Medical Center and University of Kansas.

Activities: QVIC engages in three activities: 1) regional quality improvement projects using mixed methods data: qualitative and quantitative, including hospital encounter data; 2) training and education on how to implement change; and 3) community dissemination and engagement. Exemplary projects include:

- Opioid management: examining the implementation of electronic health records (EHRs) in four regions to understand their impact on clinical workflow and patient outcomes related to pain management.
- Transitions of care for heart failure: evaluating the implementation of interventions and tools to improve transitions in care following hospitalization and their impact on subsequent emergency department visits and hospital readmissions.

Collaborators: QVIC is working with 15 hospitals in the Kansas City region as well as community-based organizations (including the [Mid-America Regional Council](#)), researchers, and payers.

Data & Tools: QVIC research projects make use of clinical data from hospital EHRs and hospital encounter data collected by the [Hospital Industry Data Institute](#) (*see separate profile*). A limitation of this data is lack of information on ambulatory care, pharmaceuticals, and the prices paid for services to assess cost effectiveness. QVIC has had preliminary conversations about access to clinical data from health information exchanges (HIEs) serving the state as well as conversations with MHI or other CMS Qualified Entities (QEs).

Funding: QVIC has received federal funding through the National Institutes of Health's [Clinical and Translational Science Awards Program](#) and philanthropic support from [BioNexus KC](#) and the [Marion and Henry Bloch Family Foundation](#) in Kansas City.

Future Plans: Leaders of QVIC are seeking to build a sustainable business model by demonstrating the value of the consortium's work to hospitals or payers. They expressed interest in using data from statewide (Kansas and Missouri) all-payer claims databases to enhance the utility, integrity, and efficiency of their research.

Missouri Primary Care Association

Purpose: The mission of the [Missouri Primary Care Association](#) (MPCA) is to be Missouri's leader in shaping policies and programs that improve access to high-quality, community-based, and affordable primary health services for all Missourians.

Formation & Governance: Founded in 1984, MPCA is governed by a board of directors representing its member health centers.

Members & Service Area: MPCA is a network of 28 community, migrant, and homeless health centers across Missouri that serve more than 500,000 patients at 200 locations. Health centers provide comprehensive primary and preventive care to people living in underserved areas, regardless of their ability to pay. Some health centers have entered into value-based payment arrangements with managed care organizations, which share member rosters, claims data, and information on care gaps to support better care management.

Services: MPCA offers advocacy and support services for its members including emergency preparedness, health center and workforce development, and outreach and enrollment efforts. The Association works with members and partners on quality and performance improvement initiatives including implementation of the patient-centered medical home, behavioral health and pharmacist integration, chronic care and pain management, and oral health. MPCA assists members with data analyses to examine questions, such as the need for obstetrical care in a particular area.

Infrastructure & Tools: MPCA maintains a [Population Health System](#) that aggregates patient encounter data from the electronic health record (EHR) systems of member health centers. The database also includes information on hospitalizations through a linkage with the Midwest Health Connection health information exchange. The Association also aggregates data on health-related social needs, which health centers collect using a [standard screening tool](#) built into EHRs.

These data are used for federal and state reporting, performance benchmarking, and quality improvement efforts. The network convenes MPCA members to share best practices, resolve technical issues, and improve patient outcomes through peer-to-peer collaboration and technology-enabled health information exchange initiatives. Health centers can use these tools to plan clinical care, help patients manage chronic diseases, and report on quality of care.

Funding: MPCA is funded through member dues and fees as well as federal and state grants and contracts.

Future Plans: MPCA will continue working with health centers and state/federal partners to provide patients with the highest quality of health care. MPCA plans to continue using population health data to support value-based care initiatives and improve the overall health care of patients served by community health centers.

University of Missouri Center for Health Policy

Purpose: The [Center for Health Policy](#) (CHP) at the University of Missouri–Columbia is an objective, nonpartisan center of excellence committed to addressing questions of access to quality, affordable health care. CHP activities include education initiatives, summits, conferences, research, outreach, and communication. Areas of focus include:

- improving the quality and efficiency of [MO HealthNet](#) (Missouri's Medicaid program)
- improving health literacy
- reducing health disparities
- ensuring an adequate health care workforce in Missouri
- expanding health insurance coverage in both the private and public sectors
- expanding rural and urban access to services via innovative [telehealth interventions](#)
- reducing childhood obesity.

Formation & Governance: The University of Missouri–Columbia School of Medicine developed the CHP in 2002 to foster dialogue and analysis of health policy issues important to the welfare of Missourians. Human subjects research conducted by CHP requires approval from an institutional review board.

Collaborators: CHP engages collaborators from academia, public and private communities, interest groups, community partners, state and local agencies, and elected officials. In 2007, CHP and Washington University's Center for Health Economics and Policy established the [Missouri Health Equity Collaborative](#) with support from Missouri Foundation for Health and, subsequently, the Health Forward Foundation.

Data Uses: CHP and the [Office of Social and Economic Data Analysis](#) (OSED) at the University of Missouri provide ongoing research and analysis on the MO HealthNet program under contract with the Missouri Department of Social Services (DSS). Recent analyses have included an examination of atypical anti-psychotic medication use in children and evaluations of the Medicaid Transformation Grant, Money Follows the Person, and the Chronic Care Improvement Programs. Analyses have linked Medicaid claims with data from other sources including electronic medical records, Supplemental Nutrition Assistance Program (SNAP), a cancer registry, and birth and death records. CHP and OSED provide technical assistance to DSS and conduct an annual evaluation of MO HealthNet.

Future Plans: CHP recently signed a business associate agreement with the [Midwest Health Connection](#), part of Velatura Health Information Exchange (HIE) Organization, to allow data matching to understand differences in care patterns for Missourians covered by Medicaid and other types of health insurance coverage.

Washington University Institute for Public Health

Purpose: The [Institute for Public Health](#) was founded in 2008 to harness the strengths of Washington University to address complex health issues and health disparities facing the St. Louis region and the world. The vision for public health at Washington University is to improve community and global health through creation of new knowledge, application and translation of science, and training of advanced academic and practice leaders.

Activities: The Institute carries out its mission through seven centers and several initiatives and programs that together act as:

- Connectors to improve, amplify, and support public health efforts in St. Louis and around the world.
- Conveners to bring together faculty and scholars across diverse disciplines to share knowledge, form partnerships, and turn ideas into action.
- Catalysts to inspire innovative solutions to pressing public health challenges through targeted events, seed funding, and other opportunities.

Collaborators: The Institute collaborates with community partners and government agencies on projects and initiatives such as creating a regional data sharing capability to help local and state agencies track and respond to the COVID-19 pandemic. Institute researchers regularly collaborate with the [St. Louis Integrated Health Network](#) of hospitals, community health centers, and other safety-net providers partners to conduct research and implement an evidence-based approach to local health care delivery. The Institute's Center for Public Health Data and Training collaborates with the University of Missouri to support the St. Louis [Regional Data Alliance](#).

Data & Tools: The University's [Center for Administrative Data Research](#) maintains centralized data resources and expertise for use by researchers. The Institute's faculty make use of Medicaid and Medicare claims and other data to examine opportunities to improve health care access, quality, and affordability in Missouri and nationally. For example, researchers from the Center for Health Economics and Policy used Medicaid data to examine effective payment policies and utilization and access for treatment of chronic diseases such as diabetes and obesity. The Center's researchers have sought, but not been granted, access to clinical data from a health information exchange that would have been useful for examining regional care patterns (e.g., how the COVID-19 pandemic affected care seeking for people with heart conditions).

Funding: The Institute's work is funded through university support, gifts, and grants.

Future Plans: The Institute is seeking opportunities to link health data with other public data to plan and evaluate interventions for addressing the social determinants of health. The Institute's leaders are supportive of efforts to create a statewide all-payer claims database and are interested in contributing the University's expertise to help facilitate partnerships that would bring Missouri's data assets together to advance public health.