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# **Recommendations to Expand Access to and Use of the Minnesota All Payer Claims Database: Final Report**

**REPORT TO THE MINNESOTA LEGISLATURE**

September 2023

**Recommendation Report for Expanded Access to and Use of the Minnesota All Payer Claims Database:  
Final Report**

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September 2023

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237 State Office Building

To the Honorable Chairs and Ranking Members:

In recognizing the value that data-driven health policy initiatives can bring to delivery system improvement, the 2021 Minnesota Legislature directed MDH to develop recommendations for how to expand access to and use of the Minnesota All Payer Claims Database (MN APCD), a large repository of health insurance claims, enrollment information, and costs for services provided to Minnesota residents.

This final report – a preliminary report was submitted in 2021 – is based on the experience MDH gained from the use of the MN APCD, our engagement with other states, an assessment of other states' experiences and best practices, a review of the available literature, and a series of discussions with stakeholders to enhance our understanding of needs and potential use cases of the MN APCD. MDH's national leadership on the effective use of APCDs — through board membership on advocacy organizations, participation on a federal advisory board, and discussion with federal partners — has been an asset in the development of these final recommendations.

In brief, we found the following nine recommendations will set MDH on a path toward further enhancing the data infrastructure required for data driving health policy making and generating applied research findings to improve access and cost of health care in Minnesota:

- Authorize access to and use of the MN APCD for a public benefit.
- Create alignment across authorized uses of the data.
- Direct MDH to provide curated access to the data for individuals and entities that can demonstrate use of the data for a public benefit to Minnesotans.
- Direct MDH to develop and implement a clear and robust oversight process for new data access.
- Direct MDH to develop interagency agreements governing access to the data by state agencies, subject to demonstrated business needs by those agencies.
- Direct MDH to explore a joint powers agreement between the State of Minnesota and the University of Minnesota to encourage the effective and efficient use of the MN APCD, including in support of state business needs.
- Direct MDH to develop a fee schedule for the use of the data that offsets some of the costs associated with expanding and maintaining data access and use. Data access fees should not present financial barriers to communities most affected by disparities.
- Direct MDH to enhance data currently collected in the MN APCD to increase value to the state.
- Direct MDH to reduce barriers to data access and use with the goal to advance health equity.

Please direct any questions about this report or the ongoing work that relies on the MN APCD to Stefan Gildemeister, the State Health Economist at (651) 201-4520 or [stefan.gildemeister@state.mn.us](mailto:stefan.gildemeister@state.mn.us).

Sincerely,

A handwritten signature in black ink that reads "Brooke A. G." followed by a long horizontal flourish.

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Enclosure:

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## Introduction

All Payer Claims Databases (APCDs) are large-scale databases that systematically collect health care transaction records, including medical, pharmacy, and, in some instances, dental claims. These data typically include information from multiple private and public payers on enrollment and prices, utilization of health care services, diagnostic detail, and information about servicing and billing providers. APCDs were initially developed to enhance health care transparency, meaning to publish information on variation in prices across providers. More recently, these data have been used effectively to conduct research across many disciplines, ultimately, to assist state policymakers and others to inform policy solutions associated with providing timely, affordable, and high-quality health care.

With the passage of Minnesota Laws of 2021, 1<sup>st</sup> Special Session, Chapter 7, article 3, section 42,<sup>1</sup> the state of Minnesota signaled an interest in expanding access to and use of Minnesota's APCD, the Minnesota All Payer Claims Database (MN APCD), including by directing the Minnesota Department of Health (MDH) to provide recommendations<sup>2</sup> on how to:

- Establish requirements for which outside entities may use the data.
- Determine whether data released to outside entities may identify health care facilities and providers.
- Develop an application process for outside entities to access the MN APCD.
- Consider whether to establish a data access review committee to advise MDH on selecting outside entities permitted to access the data.
- Determine how MDH will exercise ongoing oversight over data use by outside entities.
- Address steps that outside entities must take to protect MN APCD data from unauthorized use.
- Propose whether the state should participate in a state-university partnership to promote research using Medicaid data.

With renewed interest in health care reform and a focus on data-driven decision making across stakeholders and industries, many focused on containing spending growth.<sup>3</sup> The opportunity for expanded access, collection, and use of MN APCD data is happening at a critical time and serves as a catalyst for the state to take an intentional approach. This report provides **nine recommendations for expanded access and use of the MN APCD** and provides practical steps to accomplish the proposed recommendations.

To develop the recommendations and report, MDH partnered with Human Services Research Institute (HSRI), an organization with a long track record of developing and managing state APCDs, while effectively and meaningfully engaging diverse stakeholders to develop practical recommendations for data collection, analysis, and reporting.

This report is the result of a year-long process that included:

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<sup>1</sup> Chapter 7 – MN Laws. (2021). mn.gov. <https://www.revisor.mn.gov/laws/?id=7&doctype=Chapter&year=2021&type=1#laws.3.42.0>

<sup>2</sup> Chapter 7 – MN Laws. (2021). mn.gov. <https://www.revisor.mn.gov/laws/2021/1/Session+Law/Chapter/7/>

<sup>3</sup> Section 1: MN Health Care Spending and Cost Drivers. <https://www.health.state.mn.us/data/economics/chartbook/docs/section1.pdf>

1. Synthesizing information on the MN APCD and how it is currently being used ([Appendix A](#));
2. Comprehensively reviewing APCDs in other states and interviewing their leaders, examining current practices in Minnesota, and documenting best practices in an environmental scan that allows Minnesota to benefit from lessons learned elsewhere ([Appendix B](#));
3. Drafting a preliminary recommendation report to the legislature ([Appendix C](#)); and
4. Engaging with a variety of stakeholders in Minnesota who could benefit from expanded access, collection, and use of the MN APCD ([Appendix D](#)).

## Recommendations for Expanded Access to and Use of the MN APCD

In the development of recommendations in this report, the research team confirmed: expanded access to and use of the MN APCD will increase the scale of evidence generated from the data and the types of questions that can be answered with the data, bring new expertise to analyzing the data, and increase knowledge to aid in the transformation of health care delivery in the state. An expansion would create opportunities to better understand treatment prevalence in Minnesota, how clinical care and health care costs interact, and how access to critical therapies varies across the state and its residents. An intentional data governance process will guarantee clear and predictable access to users outside of MDH, while ensuring data security and the privacy of personal information included within the data.

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### *All Payer Claims Databases (APCDs)*

*Large-scale databases that systematically collect health care transaction records, including medical, pharmacy, and dental claims. These data typically include information from multiple private and public payers on enrollment and prices, utilization of health care services, and provider detail.*

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**Based on our analysis, observed best practices, and considering the potential resulting benefits to Minnesota, MDH recommends the Legislature adopt the following nine recommendations. Specifically, the Minnesota legislature should in statute:**

1. Authorize access to and use of the MN APCD for a public benefit.
2. Create alignment across authorized uses of the data.
3. Direct MDH to develop and implement a clear and robust oversight process for new access.
4. Direct MDH to provide curated access to the data for individuals and entities that can demonstrate use of the data for a public benefit to Minnesotans.
5. Direct MDH to develop interagency agreements governing access to the data by state agencies, subject to demonstrated business needs by those agencies.
6. Direct MDH to explore a joint powers agreement between the State of Minnesota and the University of Minnesota to encourage the effective and efficient use of the MN APCD, including in support for state business needs.

7. Direct MDH to develop a fee schedule for the use of the data that offsets some of the costs associated with expanding and maintaining data access and use. Data access fees should not present financial barriers to communities most affected by disparities.
8. Direct MDH to enhance data currently collected in the MN APCD to increase value to the state.
9. Direct MDH to reduce barriers to data access and use with the goal to advance health equity.

The following sections of the report provide additional detail on the recommendations and the reasoning underlying them. The appendices to this report contains substantiating information and work products developed in the process of developing these recommendations.

## **RECOMMENDATION 1: AUTHORIZE ACCESS TO AND USE OF THE MN APCD FOR A PUBLIC BENEFIT**

The Minnesota legislature should authorize expanded access to and use of the MN APCD for public benefit to further advance healthcare delivery, control costs, shape evidence-based policies, improve public health outcomes, and foster collaboration and innovation. By leveraging the rich data within the MN APCD, Minnesota can better address healthcare challenges, health inequities and promote the well-being of all Minnesotans. Once expansion is authorized, the remaining recommendations in this report support how MDH can fully realize the potential of the MN APCD and establish a framework that supports its responsible use.

## **RECOMMENDATION 2: CREATE ALIGNMENT ACROSS AUTHORIZED USES OF THE DATA**

The Minnesota statute governing collection, maintenance and use of data has evolved over time in response to specific data and policy needs, including by authorizing specific studies or directing the development of public use files to enhance the value of the MN APCD. This has already contributed to some misalignment across data products. With expanded access, there is a chance for further misalignment in the statute between using summary data, developing public use files, and direct access provisions. The first recommendation is to create alignment in the statute between data access and use provisions to effectively implement expanded data access.

These changes should include:

- Removing the sunset to the state’s authority to conduct research using the MN APCD in Minnesota Statutes, section 62U.04, subdivision 11(d).
- Permitting the naming of provider organizations and clinic sites, currently prohibited in Minnesota Statutes, section 62U.04, subdivision 11(b).
- Authorizing MDH to identify payer and provider organizations in the development of Public Use Files, currently prohibited in Minnesota Statutes, section 62U.04, subdivision 11, paragraph (a)(5)(ii).

As illustrated in the Environmental Scan ([Appendix B](#)), the ability to identify hospitals, provider organizations, and payers – where appropriate and in a way that prevents creating competitive advantage – has been impactful in other states by strengthening transparency, positively contributing to stakeholders’ understanding



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of their state's health care marketplace, and comparing health system performance across states. Importantly, that change would more closely align Minnesota data with transparency provisions established under a number of federal provisions. For example, the federal Hospital Price Transparency Rule<sup>4</sup> requires every hospital in the United States to provide clear and accessible pricing information for health care services online, effectively enabling the review of negotiated hospital prices such as those reported to the MN APCD. Similarly, the federal Transparency in Coverage Rule<sup>5</sup> requiring health plans to post pricing information for covered items and services, again making the reimbursement for providers public. In light of this, protecting provider identity in the public reporting of health care cost using the MN APCD is outdated.

However, Minnesota recommends creating a data access process, as described in [Recommendation 4](#), that limits how provider details may be shared publicly to prevent competitive disadvantages from emerging. In addition, to support effective expanded access to and use of the MN APCD, the legislature may wish to consider over time modifying statutory language governing the use of the MN APCD<sup>6</sup> and whether the current list of authorized use cases limit or permits new and emerging use cases. If it is deemed too limiting, it should be updated to ensure the MN APCD can be used in innovative ways.

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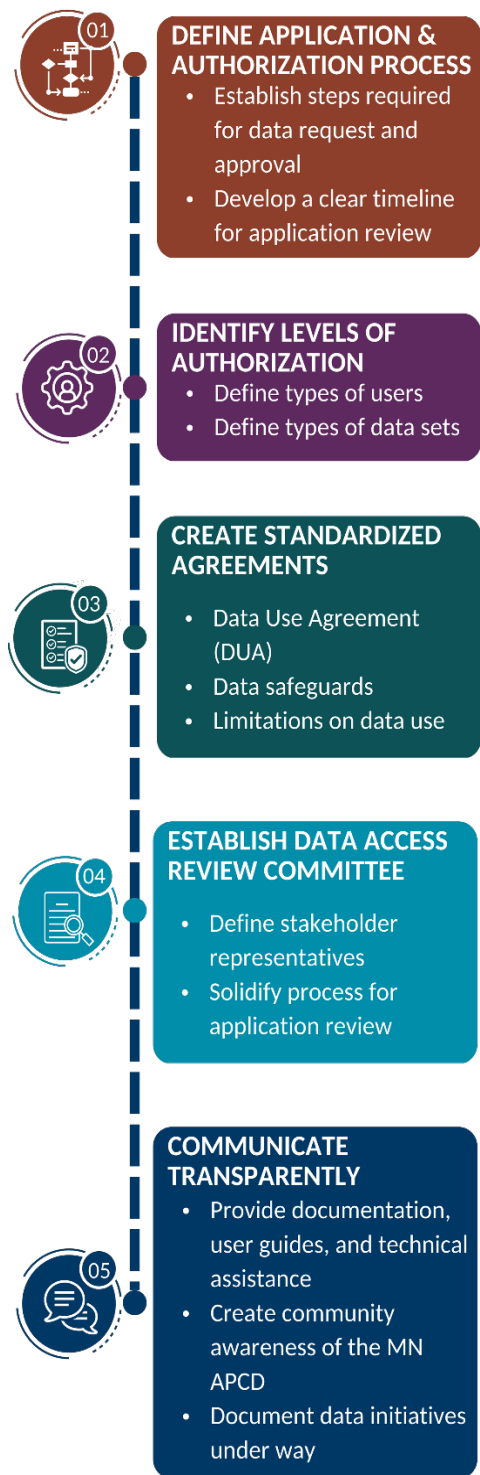
<sup>4</sup> <https://www.cms.gov/hospital-price-transparency>

<sup>5</sup> <https://www.cms.gov/healthplan-price-transparency>

<sup>6</sup> The MN APCD is governed by Minnesota Statutes, section [62U.04](#), and Minnesota Rules, chapter [4653](#), and appendices.

## RECOMMENDATION 3: IMPLEMENT A CLEAR AND ROBUST OVERSIGHT PROCESS

Figure 1. Recommended Oversight Process



Clear and robust oversight processes are essential for managing access to and utilization of healthcare data. These processes should guarantee proper usage, establish accountability for all involved parties, and facilitate research in the public interest. To ensure transparency, MDH must develop such a process that allows stakeholders to actively contribute to its creation.

There are good examples in other states from which Minnesota can learn where oversight is managed through well-designed websites and tools that help capture and share application information, including data use agreements (DUAs).

The Minnesota oversight process for expanding access to the MN APCD should:

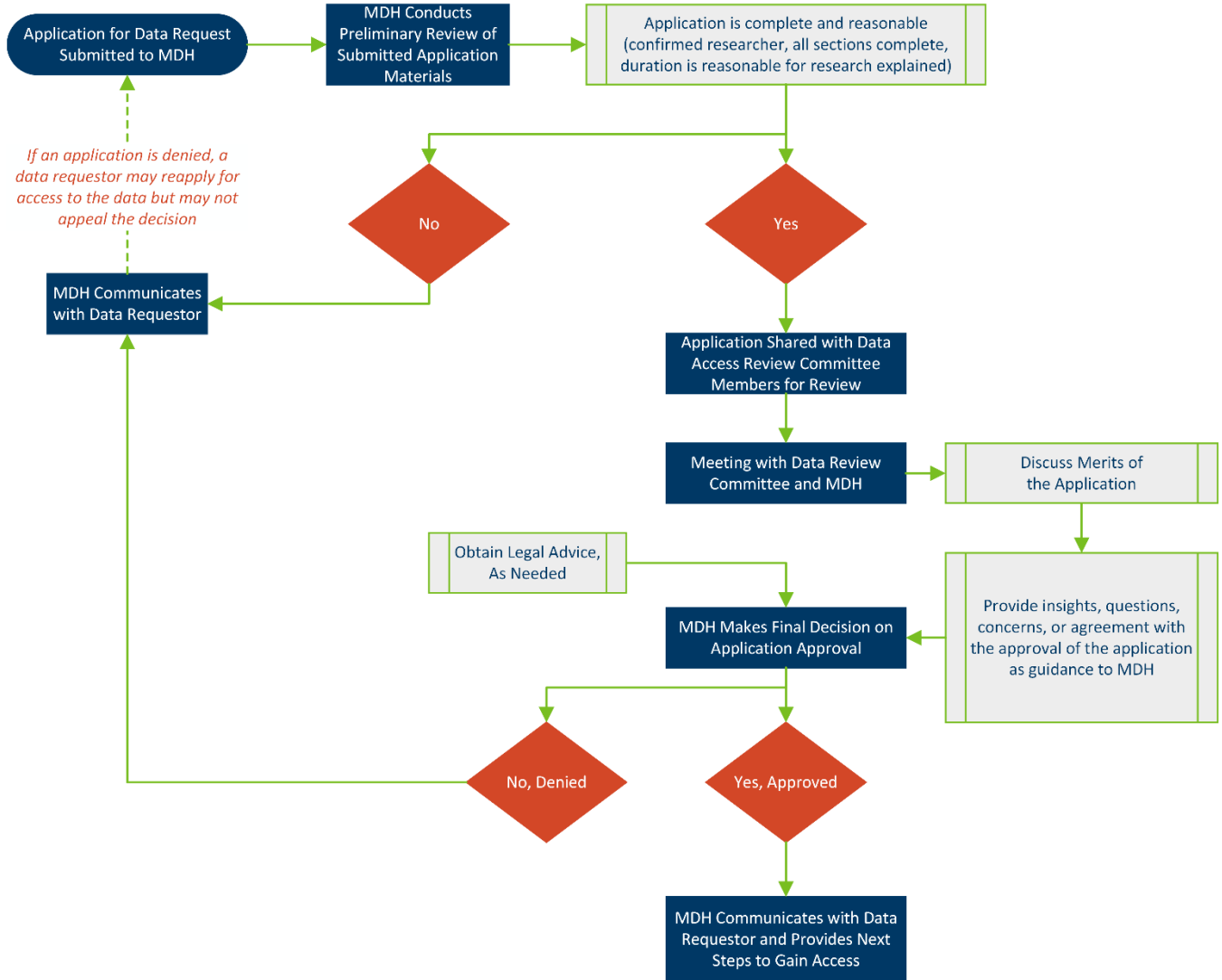
1. Articulate a process, including standard forms, for external users to apply for access to and use of the data.
2. Define levels of authorization for data use, including the granularity of data that will be available to applicants to prevent misuse of the data, such as using the data to gain an unfair competitive advantage.
3. Be centered around a DUA, governing all aspects of data access, use, security, privacy protections, reporting, review of findings, and data destruction.
4. Establish a data access review committee to advise the commissioner in approving applications, use of the data and reviewing findings.
5. Provide transparency about use of data by authorized individuals and entities outside of MDH who gain access to the data, including about how their work benefits Minnesotans, by posting this information publicly.

In summary, APCD data have been safely shared within and outside of state government environments for nearly 20 years. Expanding access to and use of the MN APCD data can be successful using a thoughtful process designed to ensure privacy protections are in place. Figure 1 highlights key features and details on proven implementation practices MDH recommends developing. The following sections provide greater detail on each of those key features.

### 3.1 Defined Application and Authorization Process

Expanded access to the MN APCD should only be available to those who are qualified to use the data for purposes that will benefit the state and its citizens. To qualify, interested users will be required to complete a comprehensive application and authorization process. MDH should develop and utilize clearly defined criteria to determine the acceptability of the applications. Figure 2 highlights the decision points in a proposed application process:

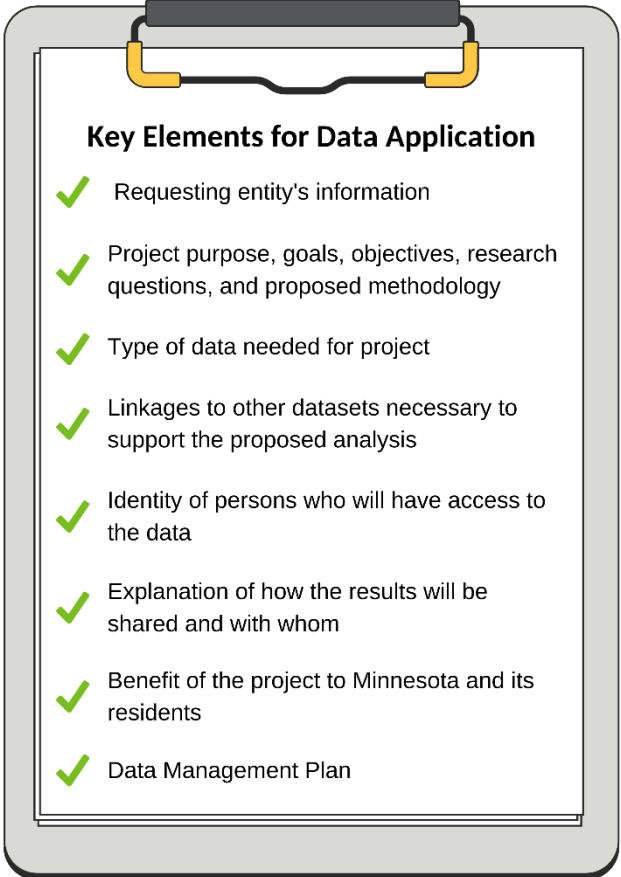
**Figure 2. Proposed Application Process**



At minimum to be approved for data access, the following eight key elements summarized in Figure 3 should be a component of a robust application. An example application is available in [Appendix E](#).

1. Name of requesting entity or individual, including role, qualifications, and prior experience with similar projects and relevant measurement sciences methods and techniques.
2. Project purpose, goals and objectives, specific research questions, and proposed methodology.
3. Type of data requested for project: Commercial, Medicaid, and/or Medicare Fee for Service.
4. Requested linkages to other datasets necessary to support the proposed analysis. (This would be subject to approval by MDH based on potential re-identification risk.)
5. Identity of individuals who will have access to the data, including the names of internal project team members and personnel for any outside data analysis or management subcontractors or consultants.
6. Explanation of how the results will be shared and with whom, and an agreement that the MDH commissioner's designee has authority, as established in the DUA (see below), to review findings prior to publication or broader.
7. A description of how the project will benefit the State of Minnesota and its residents.
8. A comprehensive data management plan should encompass compliance, documentation, and attestation. This includes providing a detailed description of data privacy and security policies and procedures, ensuring the protection of data from unauthorized access or use as mandated by the Health Insurance Portability and Accountability Act (HIPAA) Security Rule<sup>7</sup> or other relevant data privacy and security frameworks<sup>8</sup>. Users who access MN APCD data in the MDH-managed cloud-based environment will benefit from existing physical safeguards and must adhere to all applicable rules and limitations. Regardless of the data access location, MDH strongly advises implementing audit trails for all users to ensure transparency and accountability.

Figure 3. Key Elements for Data Application



It is good practice to include a statement about the potential for denial in the application since the review process will be rigorous without a guaranteed outcome; interested users should understand that prior to

<sup>7</sup> <https://www.hhs.gov/hipaa/for-professionals/security/laws-regulations/index.html>

<sup>8</sup> <https://www.hhs.gov/hipaa/for-professionals/security/index.html>

beginning an application. More details on a proposed process for application review is detailed [in Section 3.4.2 Data Access Review Committee Procedures](#).

## 3.2 Defined Levels of Authorization for Data Use

Authorization for data use can be managed in a variety of ways to ensure protection and oversight of the data. This section details how MDH could authorize the type of data user and the type or granularity of data that is available for release outside of MDH. Individuals and entities that are interested in gaining access to the data should be required to complete the application and authorization process as described in [section 3.1](#). There could be exceptions for Minnesota state agencies and the University of Minnesota, as described in more detail in described in Recommendations 5 & 6.

One possible framework that MDH could require users to adhere to is HIPAA Privacy Rule.<sup>9,10</sup> The HIPAA Privacy Rule specifies the allowance for data sharing for the purposes of public interest and benefits, as well as for research purposes as described in [Appendix F](#). Users should document their technical and research experience, as well as their compliance with data security provisions. In addition, MDH should prohibition the use of the data to gain a competitive advantage through contracting discussions by insurance companies and health care providers.

### 3.2.1 Types of Users

The development of criteria that govern eligibility for individuals and entities to access to the MN APCD is an essential component of data use authorization. MDH recommends that access provisions vary by the type of entity or user requesting access (Table 1), with access to

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### **HIPAA Permitted Uses and Disclosures**

*A covered entity is permitted, but not required, to use and disclose protected health information, without an individual’s authorization, for the following purposes or situations:*

-  *To the Individual (unless required for access or accounting of disclosures)*
-  *Treatment, Payment, and Health Care Operations*
-  *Opportunity to Agree or Object*
-  *Incident to an otherwise permitted use and disclosure*
-  *Public Interest and Benefit Activities*
-  *Limited Data Set for the purposes of research, public health, or health care*

*Covered entities may rely on professional ethics and best judgments in deciding which of these permissive uses and disclosures to make.*

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<sup>9</sup> <https://www.hhs.gov/hipaa/for-professionals/special-topics/research/index.html>

<sup>10</sup> Note: MDH is a public health agency and not a HIPAA covered entity, but that MDH employs much of the framework in securing data.

data managed separately for Minnesota state agencies and universities. The requestor types are not mutually exclusive but could be used to create different pricing or authorization structures.

**Table 1. Data Requestor Types**

Requestor Type	Description
<b>Private Entity</b>	A for-profit business or organization that accesses data or information for resale in any form.
<b>Non-Profit Entity</b>	A governmental agency or public or private organization that has been determined to be exempt from taxation under the United States Internal Revenue Code, Section 501 (c).
<b>Redistributor</b>	Any commercial or nonprofit entity that accesses data for inclusion in a larger composite database that is publicly released.
<b>Health Care Entity</b>	A health care provider, health insurance entity, or third-party administrator.
<b>Research/Educational Entity</b>	Any public or private post-secondary institution or individual affiliated with such institution.
<b>MN State Agencies</b>	Any department in the Executive Branch of Minnesota’s State Government, and any bureau, division, board, office, commission, or other entity within or created by such department.
<b>University of Minnesota</b>	Any department or individual associated with the University of Minnesota, including colleges and affiliated entities across its campuses.

### 3.2.2 Types of Data

The data application and authorization process should address the amount or granularity of data required to complete the research, as well as the ability of the applicant to comply with data security requirements that are required for granular data. All this information should be captured as part of the data request form for review and approval. Controlling the types and amount of data for release allows for MDH to provide an applicant with the minimally necessary amount of data needed based on the research and abilities of the potential user; this is the first layer of protection for data security – [Recommendation 4](#) details what these various options are. Data security and oversight begin with how much data are shared with users external to MDH. The HIPAA Privacy Rule explains in detail the ways in which data can be shared safely, which is detailed further in [Appendix G](#).

## 3.3 Standardized Agreements for Data Security and Oversight

The Data Use Agreement (DUA) is the primary protection used universally by organizations sharing health care data and is referenced throughout the HIPAA Privacy and Security Rules. A DUA should govern all aspects of data access, use, security, privacy protections, reporting, and review of findings.

Sharing DUA requirements with applicants at the time of application provides interested users with complete information on data security and oversight expectations and helps lessen redundant information on applications. The DUA can be part of an online application that allows for submission and tracking throughout the application lifecycle.

We recommend that before granting data access, an approved data user must sign a legally binding DUA, which includes requirements and agreements on data security and privacy protection specific to Minnesota. The DUA should:

- Specify the requirements for use of **data within the secure MN APCD environment**, restrictions on the use of data, duration of active credentials, and rules for publication of findings generated from approved data access.
- Outline requirements for **data files shared outside the MN APCD environment**, including security specifics and the ability of an approved user to control the environment and access to the data, as detailed in the HIPAA Security Rule<sup>11</sup> and HITECH<sup>12</sup> requirements.
- Include explicit requirements for obtaining data destruction<sup>13</sup> certificates to be returned to MDH within a set period of time upon research completion and agreement to audits to determine compliance with the DUA.

In addition to the items noted above, the DUA should meet the standards specified in the HIPAA Privacy Rule, one of the most common and best understood data protection frameworks:

- Establish the permitted uses and disclosures of the data.
- Identify who may use or receive the information.
- Prohibit the recipient from using or further disclosing the information, except as permitted by the agreement or as permitted by law.



**The MN APCD Data Enclave exists within its own secure virtual private cloud and access is limited to authorized personnel only. A common suite of analytic tools exists to allow authorized users to securely query the data and fully develop robust analyses and reports completely within the secure environment and MDH’s data governance procedures.**

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<sup>11</sup> <https://www.hhs.gov/hipaa/for-professionals/security/laws-regulations/index.html>

<sup>12</sup> <https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/administrative/enforcementrule/enfifr.pdf>

<sup>13</sup> <https://www.hhs.gov/hipaa/for-professionals/faq/575/what-does-hipaa-require-of-covered-entities-when-they-dispose-information/index.html>

- Require the recipient to use appropriate safeguards to prevent unauthorized use or unpermitted disclosure.
- Require the recipient to report to MDH any unauthorized use or disclosure of which it becomes aware.
- Require the recipient to ensure that any agents (including a subcontractor) to whom it provides the information will agree to the same restrictions as provided in the agreement.
- Prohibit the recipient from identifying the information or contacting the individuals.

An example DUA can be found in [Appendix H](#).

### 3.4 Establishing a Data Access Review Committee





As the MN APCD steward, the commissioner of health or a designee would be responsible for making the final decision on an application for data access. To ensure transparency, such decision would be best informed by input from stakeholders in Minnesota who are appointed to a Data Access Review Committee. The Data Access Review Committee should consist of individuals who provide balanced representation of the broader stakeholder community, have the ability to bring perspective on equity and health disparity to the consideration, and hold experience in data management, analytics, or research. This would ensure each member can meaningfully review applications and provide critical insights, thoughtful concerns, and a diversity of perspective to the developing recommendations for the data steward.

To work as an effective contributor to expanding the effective use of the MN APCD, the Data Access Review Committee should have a clear charge, duties, review criteria, policies and procedures, including a decision-making process and definition of a quorum. Information associated with the functioning of the Committee should be posted publicly, including application due dates, meeting times, and when final decisions will be announced.




#### 3.4.1 Committee Members

The following table provides a description of stakeholders who likely would bring important perspectives and skills to the Data Access Review Committee. Representatives from MDH, who would be members of the Committee, would bring detailed insights related to data systems, security provisions and existing practices, utility of the data, and policy considerations.

**Table 2. Stakeholders**

Stakeholders	Description
 <b>Health Insurance Company</b>	Representation from a health insurance company or a trade association for health insurance companies.
 <b>Self-Funded Payer</b>	Representation from a plan sponsor, whether a public payer like the state employee health plan, municipal health plan, or private payer, with a background in administration, analytics, or research.
 <b>Hospital</b>	Representation from a hospital, hospital system, or the Minnesota Hospital Association who can speak on behalf of its members or peers, with a background in administration, analytics, or research.
 <b>Providers</b>	A health care provider or a representative from a provider organization who can speak on behalf of providers.



Stakeholders	Description
 <b>Consumers</b>	Representation from advocacy organizations or engaged consumers with a demonstrated record of advocating health care issues on behalf of consumers.
 <b>Research</b>	Researchers outside of MDH with academic experience in health care data and cost research.
 <b>Department of Human Services</b>	Representation from the Department of Human Services, including to inform decisions about whether to permit use of Minnesota Health Care Program data.

### 3.4.2 Data Access Committee Review Procedures

Making publicly available clear and concise information on the process of applying for data and the decision-making process is an essential component of a successful program. Following are recommended procedures for the Data Access Review Committee:

1. Upon completion of the preliminary staff review, MDH distributes application(s) to all members of the committee.
2. MDH conducts regular meetings, either quarterly or more frequently.
3. The committee should meet in person or through video communication to discuss the merits of the applications; a quorum of members should be required.
4. Recommendations for approval or denial of the application are made to MDH for consideration.
5. MDH communicates the final decision through MDH to the applicant.
6. At certain intervals, MDH should provide a summary of decisions to the legislature and public.

### 3.4.3 Data Access Committee Review Policies

1. All applications should be considered confidential to protect the applicant’s intellectual property:
  - a. Members of the committee shall not share any details or information gleaned from the applications with anyone outside of the committee.
  - b. Following the review meeting, all copies of the application must be destroyed.
  - c. Review committee meetings should be held in private.
2. No member of the committee may participate in the review of an application where there is any suggestion of a conflict of interest.
3. There may be occasions when the committee decides that they need clarification on an application or need more information to make a recommendation to MDH. Policies should define:
  - a. A finite timeline, typically 45 days, for an applicant to respond to the questions or concerns.
  - b. Committee members should assess whether a recommendation can be provided based on the applicant's ability to respond definitively to the questions, or if it would be necessary to schedule a follow-up meeting to further discuss the response.
  - c. Committee members should assess whether a recommendation can be provided based on the applicant's ability to respond definitively to the questions, or if it would be necessary to schedule a follow-up meeting to further discuss the response.

4. Application review criteria should be evenly applied across all applicants. See section 3.4.4 for review criteria, with the exceptions noted in [Recommendations 5](#) & [6](#) for Minnesota state agencies and universities.

### 3.4.4 Criteria for Application Review

The following criteria should be used in making recommendations to MDH about whether to approve applicants' use of data. Recognizing that there will be capacity constraints in providing technical assistance and data systems, MDH may also use these criteria in prioritizing applications:

- Public interest contribution to the state of Minnesota and its citizens
- Technical qualifications of the applicant to ensure effective and appropriate use of the data
- Soundness of proposed methods and analyses
- Appropriateness of data requested to complete the proposed research
- Ability and commitment to adhere to best practices for data security and privacy
- Intention to publish results and findings
- Knowledge about and commitment to comply with applicable state and federal privacy laws
- Compliance with state and federal laws regarding the exchange of price and cost information – in order to protect the confidentiality of the data and encourage a competitive market for health care services
- Importance and relevance of the proposed research questions

## 3.5 Documentation and Communication

Minnesota is committed to transparency in data sharing by communicating the details of the data in the MN APCD, along with governance process and utility. A well-designed web page on the existing MN APCD website<sup>14</sup> can effectively accomplish this goal. Transparency about who has gained access to the data holds data users accountable and builds trust in data sharing process; access to what the state can learn from broader use is critical to evaluating the return on investment. At a minimum, MDH should make the following materials publicly available for prospective data users and stakeholders.

### Materials for Prospective Data Users

- Data Submission Manual**  
Lists the data elements collected, the definitions used, and the requirements for submissions
- Data Dictionary**  
Details the data included in available data sets
- Minimum Qualifications for Data Users**

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<sup>14</sup> <https://www.health.state.mn.us/data/apcd/>

**Available Technical Assistance**

A description of what technical assistance is available and the timeline in which users can expect their questions to be answered

**Processes and Policies for Data Access**

Processes and policies include the application and Data Use Agreement

**Timeline for the Application Process**

**Roster of the Data Access Review Committee**

Details on the members, policies, and procedures

**Cost Estimates**

Estimated costs associated with data access and considerations for scholarship

**Prior Research**

An overview of how the Minnesota data has been used in previous research and, to the extent available, a code library.

**Materials for Stakeholders**

**Approved Data Users & Use Cases**

Details on all users that have been approved to access the data, including:

- Name of the organization or person(s)
- Location of the data user(s)
- Dates of data shared
- Dates of use of the data (estimated duration of the project)
- Focus of study, namely the description of the purpose stated in the application for data access

**Number of Total Data Requests Per Year**

**Public posting of reports using MN APCD data**

## RECOMMENDATION 4: PROVIDE DATA ACCESS TO EXTERNAL USERS

Once a robust governance process is in place, MDH will be in the position to share data with entities outside of their state agency. As defined through the authorization process described in [section 3.2](#), prospective data users must meet the following criteria:

- Demonstrate the ability to effectively use the data
- Demonstrate capacity to protect the data
- Agree to legally binding data use agreements
- Aim to perform research that is in the public interest to Minnesota

To ensure a balance between effective data use, efficiency in data management, and appropriate oversight and monitoring, MDH should consider developing a range of methods to facilitate data access and exploring ways of deployment options over time. Considerations of how and when to deploy particular options should be informed by an initial goal of serving a broader set of users and the resource intensity of options, which would require developing a fee schedule (more on that in [Recommendation 7](#)).

The following table explains the options available to potential users of the MN APCD.

*Table 3. Data structure benefits, users, and requirements*

Data Structure	Benefits	Potential Users	Requirements
<b>Public Use File (PUF)</b>	Data summarized using the Expert Determination method described in HIPAA, which is publicly available.	Currently already available to the public on the MN APCD website.	No requirements. Available through downloadable reports and Tableau dashboards.
<b>Limited Use Data Extract</b>	An extract that only includes the data elements needed to conduct approved analysis.	Data scientists and researchers with expertise in working with complex data sets.	HIPAA allows for data sharing at this level for research purposes but requires a data requestor to specify the need for the minimum necessary data elements.
<b>Standard Data Extract</b>	An extract that includes nearly all data elements using a process known as the “Safe Harbor Method.” This allows for the creation of a single extract rather than customizing an extract for each request.	Data scientists and researchers with expertise in working with complex data sets who do not need to access a five-digit zip code.	HIPAA allows for data sharing without adherence to the minimum necessary rule when a zip code is limited to the first three digits and ages are anonymized after a person turns 89.
<b>Simplified Custom Files</b>	Files referred to as “flat files,” containing data elements required for approved analysis. These files will be further limited to the needs of the requestor.	Data analysts who are data-savvy but do not have experience working with referential data tables.	The minimum necessary process should be adhered to by MDH as they prepare data files for research purposes to users approved through the rigorous application process.
<b>Custom Reports</b>	A custom report is a summary of tables and analyzed data that can be interpreted by the recipients. This type of file is the most customized and labor-intensive.	Those in the community who need information from the data but do not have the skills or resources to drill into the data themselves.	This type of summary reporting using expert determination and cell suppression mitigates the risk of sharing the data.

As part of the consideration of how to make data available, MDH should develop capacity to permit users to work within its secure data enclave as well as generate data files for use externally that meet certain, articulated data privacy requirements.

## **RECOMMENDATION 5: DEVELOP INTERAGENCY AGREEMENT FOR STATE AGENCIES**

As described in [Recommendation 3.2](#), state agencies seeking to utilize the MN APCD should face a streamlined application and authorization process. This is an efficient and reasonable approach, given that state agencies share IT systems, operate under aligned policies and procedures for data security, and hold state employees to the same standard for privacy and requirements for data use this creates. Similar to other states employing this process, MDH should still establish legally enforceable Interagency Agreements (IAA) that govern, among other things:

- Levels of data access and privileges
- Proper use of the data, including appropriate use in publication
- Benefits to their team and their agency's stakeholders within the state of Minnesota
- Associated costs to support the MN APCD

An IAA would also outline the allowed uses of the data, the agreed cost sharing between agencies, and reporting requirements, including review by the APCD agency if appropriate.

Implementing an IAA process would establish a long-term, effective solution for data users within the state using the MN APCD. Such an agreement would eliminate the need to include each individual project in the data request and review process. The agencies would be permitted to have state employees access the data and/or hire a qualified vendor to access and use the data on their behalf and under the terms and conditions of the IAA.

## **RECOMMENDATION 6: EXPLORE A JOINT POWERS AGREEMENT WITH THE UNIVERSITY OF MINNESOTA**

The University of Minnesota and affiliated Centers have been effective partners to MDH in research and analysis for years; faculty and staff are also competent researchers on their own across multiple disciplines. In order to facilitate the efficient utilization of the MN APCD and to tap into the university's diverse expertise for research in the public interest, MDH should consider the possibility of creating a joint powers agreement with the University of Minnesota. Given the university's status as a state institution and a land-grant university, it should be considered for access under a broader authority.

A joint powers agreement governing streamlined data access and use between MDH and the University of Minnesota could govern the cooperation between both entities to conduct research, provide analysis services, and, as appropriate training or documentation. This would permit the establishment of a long-term legal relationship with multiple users and allowed uses. Users (and uses) would still need to be internally vetted by the University of Minnesota prior to receiving access to the data, and their access would be governed by the provisions in the joint powers' agreement. We recommend that faculty and students at other universities, Minnesota based and beyond, would still have the opportunity to access the MN APCD, but would follow the standard process outlined in [Recommendation 3](#).

## RECOMMENDATION 7: CREATE FEE SCHEDULE

The legislature currently funds basic MN APCD functions roughly related to collecting data, working with data submitters to ensure data quality, housing the data in the MDH data ecosystem and maintain rigorous data protections, developing and presenting data in public use files and data dashboards, and conducting research. Establishing a carefully managed expanded use initiative for the MN APCD comes with additional activities and some expansion of existing ones, including:

- Developing and maintaining website materials and policy documents targeted at potential new users.
- Performing key new facilitation functions associated with the initiative, including communication, developing and maintaining data use provisions, managing an advisory committee, reviewing applications and research products, and developing training materials and documentation.
- Generating extracts or data files upon approval of applications.
- Providing technical assistance to data users and, as appropriate, generating custom tables or otherwise supporting users.
- Synthesizing information from approved projects for reporting to the legislature.

There would also be additional technology support which most likely includes:

- The establishment of a Virtual Private Network (VPN) through which approved users will need to gain access to the data enclave.
- The management of appropriate privileges within the data environment to maintain security and privacy requirements.
- Additional storage space for new user dataset (limited, standard, etc.) access and for users to save their own analyses.

These requirements could be funded through a variety of financing mechanisms, including the following ones used by other states (often in combination).

State Government Funding Opportunities	Federal Funding Opportunities	Grant Opportunities	User Fees
<ul style="list-style-type: none"> <li>• Payments to the APCD for use of the data or for production of customized reports</li> <li>• General funds appropriations</li> <li>• Insurance Department assessment fees on public and private payers</li> </ul>	<ul style="list-style-type: none"> <li>• Medicaid dollars (90/10 funds) support APCD work in many states when used for Medicaid analysis</li> <li>• Requires joint application process with state Medicaid agency</li> </ul>	<ul style="list-style-type: none"> <li>• Made available directly to the state APCD agency or through other state agencies doing a study using the data</li> </ul>	<ul style="list-style-type: none"> <li>• Subscription fees</li> <li>• Assessment fees</li> <li>• Licensing fees</li> <li>• Tiered usage fees</li> <li>• Other creative solutions</li> </ul>

We recommend the legislature considers establishing an appropriation to implement the program and finance basic capabilities and requires data users to offset programs costs through data use fees. Fees could depend on how many types of data are requested (e.g., medical, pharmacy), how many years of data are sought, and the type of requesting entity (e.g., commercial, nonprofit, university). Fees should not present financial barriers to communities most affected by health disparities. As such, the financing of the expanded use in Minnesota should permit providing waivers or scholarship opportunities to those who cannot afford to pay fees or cannot pay the full amount.

We also strongly recommend that the legislature directs MDH to partner with the state Medicaid program to support analytic and policy use cases that could help enhance the value of Medicaid. Most states use this partnership to obtain Medicaid financial support of their APCD efforts. More information can be found in the [environmental scan](#).

## RECOMMENDATION 8: ENHANCE DATA COLLECTION

Compared to many other states, Minnesota currently maintains a fairly lean data collection approach. MDH’s current data submission requirements<sup>15</sup> do not include several data elements that, as documented in the environmental scan, other state APCDs have used to enhance understanding of the health care marketplace and aspects of health equity in their states. The table below highlights data elements that we recommend the legislature should require MDH to add to the MN APCD to increase the overall utility and value of the data. Adopting these data would increase the value of the MN APCD to state policy makers.

**Table 4. Additional Data Elements**

Data Element(s)	Application in Minnesota
<b>Race, Ethnicity, and Language</b>	Collecting race and ethnicity data will strengthen Minnesota’s capacity to measure variation in health care use, prices, and spending patterns among Minnesota residents to better understand social determinants of health and ultimately enable policy change to strengthen equity.
<b>Coverage Type &amp; Group Name</b>	More complete eligibility data would help Minnesota better understand variability in health care use and costs across the marketplace, including self-funded vs. fully insured enrollees. It would also understand to what extent benefit and price contribute to that variation

<sup>15</sup> <https://www.health.state.mn.us/data/apcd/encounterdata/index.html>

Data Element(s)	Application in Minnesota
<b>Dental Claims Files</b>	Collecting dental claims data will provide a more accurate understanding of dental care use and services in Minnesota, providing opportunities to address oral health challenges in the state.
<b>Non-Claims Based Payments</b>	All payments made to providers that are not included in Fee for Service models of contracting. These data would assist with obtaining a more complete picture of health care spending in Minnesota and payments made to incentivize certain outcomes.

## 8.1 Additional Enhancements to Consider

In addition to the data elements shown in Table 4 above, the following four enhancements to the MN APCD, which are further discussed below should be considered:

1. Collect direct patient identifiers.
2. Continue to encourage voluntary submission from ERISA-preempted self-funded payers.
3. Adopt the APCD Common Data Layout.
4. Collect data on social determinants of health other than those identified in Table 4.

### 8.1.1 Collect Direct Identifiers

Currently, direct identifiers are not reported to the MN APCD, data are de-identified prior to data submission to the state. The availability of individually identifiable data elements such as first and last name, date of birth, street address, and social security number will enhance data quality by allowing the state and data users to have confidence that each anonymous person in the data is a unique individual. It might also assist, where appropriate, with building trust with provider systems in the case of provider reporting, in that providers could validate their attributed patient populations. Only two states, Minnesota and New Hampshire, hash Personally Identifiable Information (PII) during the data collection process, meaning they receive de-identified data. Most state APCDs collect data fully identified and then encrypt them [using what is called a hashing algorithm] in their data systems. Following the establishment of a robust unique identifier, PII information is separated from the data itself for data privacy purposes; analysts do not typically have access to identified data.

**Following are a few applications associated with use of PII:**

1. **Enable robust analysis over time:** The capability to standardize the data and establish reliable individual identifiers or a master person index enables the linkage of data across different payers and over time. This allows for a more comprehensive picture of the history of insurance coverage, including transition in coverage, access (or lack of access) to care, use of primary care services, progress of chronic disease, and other themes that are important for monitoring population health and health equity. For example, the process of developing nationally recognized health care



performance measures often assumes the ability to track individuals for multiple years in the source database.

2. **Data linkage to enhance data value:** The availability of PII data elements would also create opportunities to enable analyses that would be stronger with data not typically available in APCDs. Supplementing the available information in APCDs with individual-level data from other state data sources, such as electronic health record data, vital statistics, or cancer registries could create powerful evidence and would be advantageous in “both directions”. For example, these linkages would be useful for cancer registry data users who are interested in understanding the cost of cancer care by treatment type. Relatedly, MN APCD data users who are looking for population disparities based on the stage of cancer at initial diagnosis couldn’t do this without data from the cancer registry.

Similarly, making detailed address information of health system users available to certain MN APCD analyses can support a multitude of use cases, one of which is being able to create statistics at a more granular level than county level or even than ZIP code tabulation areas. This is particularly important for analyses of inequities, which, because of the geographic size of counties and ZIP codes, typically require more granular data. Through geocoding of address information and assigning geographic identifiers, linkages to aggregated national and state data resources are possible, such as linking to U.S. Census Bureau data at the census tract level. These linkages can support analyses informed by the neighborhood context where the person lives—i.e., having information on percent of population in poverty, percent of population that is unemployed in the neighborhood or census tract of residence—by enhancing the APCD with area-based social determinants of health information.

Again, other state APCDs have succeeded in demonstrating that careful management of identifiable information can be taken in by states without risking re-identification of patients or otherwise impacting data privacy.

### *8.1.2 Encourage Voluntary submission from ERISA-preempted self-funded payers*

Employers are key stakeholders in the evolution of health care systems. As expected, when exposed to the MN APCD as a tool to increase transparency, for benchmarking and to assess the effectiveness and quality of care delivered in the health care system, employers are incredibly engaged. However, following a Supreme Court decision in 2016, Minnesota, like other states, has experienced losses in self-funded payers’ claims. With their enrollees representing about 60 percent<sup>16</sup> of Minnesota’s commercially insured population, this has created sizable gaps in the MN APCD that analysts look to overcome with statistical methods. Several states, such as Colorado and Maine, have successfully encouraged voluntary participation by providing evidence of the ways employers can use the APCD data to save costs and improve the health of their employees. Minnesota should do the same by:

1. Developing communication material aimed at encouraging participation by self-funded employers.
2. Producing benchmark data for use by self-funding employers during negotiation.
3. Seeking to developing direct relationships with these employers, starting initially with the largest ones.
4. Partnering with Third Party Administrators, or other entities that facilitate developing benefit design, network use and claims processing for self-funded employers, to remove any existing barriers.

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<sup>16</sup> Minnesota Department of Health, Health Economics Program, Health Care Market Chartbooks, Section 2; <https://www.health.state.mn.us/data/economics/chartbook/index.html>

### 8.1.3 Consider Adopting the APCD Common Data Layout (APCD-CDL™)

National APCD leaders, along with states, payers, and federal agencies are joining together to advocate for a common standard to allow for multi-state comparisons and reduce the reporting burden for data submitters that produce data for multiple states. The Department of Labor’s (DOL) State All Payer Claims Databases Advisory Committee<sup>17</sup>, in particular, recommended states use APCD-CDL™ as a national standard, in part to bolster collection of the ERISA self-funded data.

Minnesota should carefully weigh the barriers to adopting a national standard – the disruption in services, the cost, the need to crosswalk data across data models, and the additional effort for data submitters – against the considerable benefits in the state’s decision-making.

### 8.1.4 Collect data on social determinants of health

Fully taking advantage of the MN APCD would mean reporting across demographic groups of relevance, including by considering groups defined by non-medical factors that influence health outcomes. To enhance Minnesota’s understanding of disparities, Minnesota should collect data on social determinants of health (SDH)<sup>18</sup>, where available in payer data. Where data are not currently collected by payers in Minnesota, MDH should work with the Minnesota Administrative Uniformity Committee to require the collection of these data and define specifications.

The National Association of Health Data Organization (NAHDO) recently published a White Paper describing standards and collection practices that support the reporting of SDH to APCDs. The paper summarizes SDH data available in standard insurance transactions and should be used by MDH to guide its efforts<sup>19</sup>. Recommendation 9 further details how MDH can support advancing health equity efforts using these data.



**APCD data alongside and linked with other health and social determinant of health data can provide a powerful tool to understand where disparities exist, to prioritize resource and policy improvements, and track the impact of resource and policy investments.**

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<sup>17</sup> <https://www.dol.gov/agencies/ebsa/about-ebsa/about-us/state-all-payer-claims-databases-advisory-committee>

<sup>18</sup> SDH, as defined by the World Health Organization,<sup>18</sup> are the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies, and political systems.

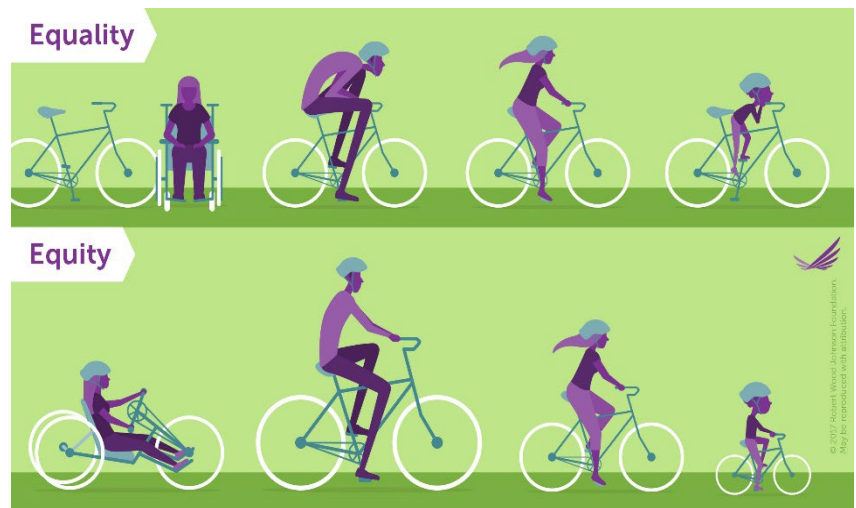
<sup>19</sup> <https://www.apcdouncil.org/publication/social-determinants-health-apcd-and-hospital-discharge-data-standards-and-collection>

## RECOMMENDATION 9: ADVANCE HEALTH EQUITY

Minnesota should reduce barriers for data access and to use the MN APCD to advance health equity. Health equity means everyone has an equal opportunity to live a long and healthy life regardless of race, ethnicity, gender, income, neighborhood, education, or any other social condition. APCDs are being used to examine health care utilization and spending across different population subgroups, such as race, ethnicity, income level, and geographic location. The inclusion of personally identifiable information (PII) data elements in the APCD is crucial for effectively evaluating the presence of health disparities. This can support identifying the most vulnerable demographic groups within the insured population (particularly in terms of race or residential location), facilitating policy adjustments that enhance the well-being, health, and healthcare systems of Minnesotans, and monitoring the progress made in implementing these policies.

As described above in Recommendation 8.1.4, MDH should evaluate options to incorporate health equity data into the MN APCD to identify and address disparities. In addition, to advance health equity, MDH should:

- Develop a training curriculum aimed at community organizations without traditional research capabilities, covering what research questions the data could address and how to use the data and available data tools.
- Offer community and advocacy organizations dedicated technical assistance and support for data analysis to advance a research agenda.
- Develop community based participatory research partnerships that respect data sovereignty.
- Partner internally at the state, such as with MDH’s Center for Health Equity<sup>20</sup>, to ensure they are aware of the MN APCD as a data source to support their efforts. Inter-agency agreements, as described in [Recommendation 5](#), will help support these efforts.
- Partner with the University of Minnesota, including the Program in Health Disparities Research<sup>21</sup>, whose mission is to promote health equity through collaborative research, innovation education, and trusted partnerships, to ensure they are aware of the MN APCD as a data source to support their efforts and use the data, as appropriate. Having a joint powers agreement, as described in [Recommendation 6](#), will help support these efforts.



<sup>20</sup> <https://www.health.state.mn.us/communities/equity/index.html>

<sup>21</sup> <https://med.umn.edu/healthdisparities>

There are a multitude of ongoing approaches and efforts to explore and discuss to create a comprehensive data-driven approach, as opposed to implementing siloed efforts. MN APCD data, alongside and linked with other data on health, health care, and social determinants of health can provide a powerful tool to understand where disparities exist to prioritize both resources and policy improvements. These tools can also be used to track the impact of resource and policy investments. The National Academy for State Health Policy has put together a set of resources for states to address inequities using data strategies<sup>22</sup> that provides both guidance and examples of efforts other states have undertaken.

## Conclusion

The MN APCD has been considered a leader in the use of All Payer Claims Data for many years, by its peers, the federal government and research partners, and MDH continues to produce quality reports and insights using the data; however, due to the current constraints in scope of the data and use established in law, the state of Minnesota and its residents do not yet fully benefit from a number of innovative uses that many of the other APCD states employ. Along with the recommendations detailed in this report, the adoption of best practices from other state APCDs and national organizations can propel the MN APCD as a more accessible, usable and impactful data set for qualified stakeholders to engage with that will benefit the statewide health care landscape and health of all Minnesotans.

Critical to the development of recommendations with these reports have been yearslong relationships MDH developed with a range of stakeholders and research partners, as well as new engagement with a broader set of stakeholders pursued during the process of developing this report (see [Appendix D](#)). Though not a formal or standalone recommendation, implementing any new work along the lines of recommendations in this report will require ongoing, strong and active engagement with data submitters, data users, community organizations, employers, and the research and policy community. This will help maximize the return on investment to Minnesota residents that the state's legislature has made by developing and maintaining these data. As noted, with the right kind of approach, the University of Minnesota and its faculty and staff, can be a resource in this effort, as can be MDH's partner agencies, the Departments of Human Services and Commerce.

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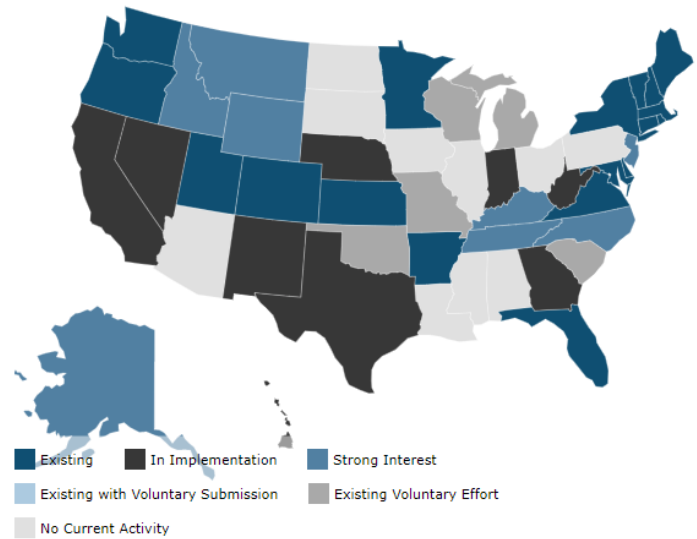
<sup>22</sup> <https://www.nashp.org/using-data-strategies-to-advance-health-and-racial-equity/>

## Appendix A: Background and Process

### BACKGROUND

As large-scale databases that systematically collect health care transaction records, All Payer Claims Databases (APCDs) include medical, pharmacy, and dental claims. These data typically include information from multiple private and public payers on enrollment and prices, utilization of health care services, and provider detail.<sup>23</sup>

APCDs were initially developed to enhance health care transparency and are growing in popularity across the country, with most states adopting the model (see Figure 1A). More recently, these data have been used to assist state policymakers and others to address many of the challenges with providing timely, affordable, and high-quality care. State APCDs operate in a variety of ways; some are housed within the Department of Health like in Minnesota, some are run through appointed administrators such as the Center for Improving Value in Health Care (CIVHC) in Colorado, while others have shared responsibility between the Medicaid Office and Department of Insurance as in New Hampshire. Since no two states are set up the same, no state is directly comparable but best practices were gleaned to support expansion of the MN APCD. Most states provide processes, policies, and practices for data sharing among state agencies and for data release to qualified entities and researchers to make use of the data to benefit their state’s residents.



**Figure 1A. APCDs Across the United States: ©2009 - 2023 UNH, the APCD Council, and NAHDO. All rights reserved.**

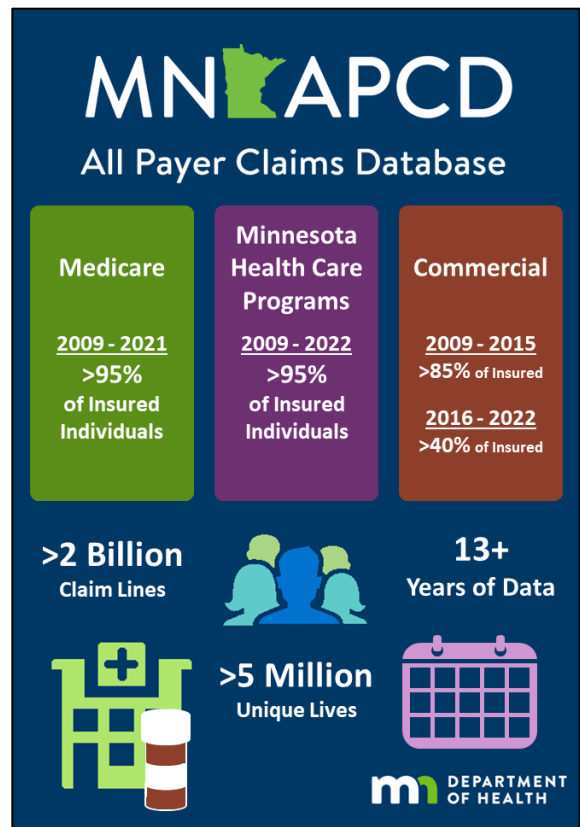
MDH produces valuable research using the MN APCD, but adopting the recommendations put forward in this report will ensure that Minnesota can participate in interstate data sharing studies and take advantage of lessons learned from other states to benefit Minnesotans through this data asset. Through the expansion of the MN APCD, there will be additional opportunities for the state to see a financial return on health care savings through their continued and expanded investment in this resource. In addition, the stakeholder engagement has the added benefit of not only increased awareness of the MN APCD, but the potential of increased use to ensure that data-driven health care decisions are at the center of health care reform and population health and health equity efforts. This increased collaboration can reduce the burden of additional data collection, and in addition if the MN APCD can be looked to as *the* resource for health care expenditures in the state, this collaboration will lead to the MN APCD being seen as a resource for quality data that can lead to actionable insights.

<sup>23</sup> All-Payer Claims Database (APCD) Council. (2014). The Basics of All-Payer Claims Databases: A Primer for States. *Institute for Health Policy and Practice (IHPP)*. <https://scholars.unh.edu/ihpp/125/>

## MN All Payer Claims Database

Figure 2A. MN APCD — By the Numbers

- 2008**  
Established in 2008 as part of a bipartisan reform package, the MN APCD aimed at enhancing transparency about the value of health care, meaning improving health care quality and reducing costs.<sup>24</sup>
- 2014**  
In 2014, the Minnesota Legislature refocused the use of the MN APCD toward the development of research activities on cost, quality, access, and disease burden, including the production of public use files (PUFs). Since 2014, MDH has made available summary data generated from the MN APCD in the form of Public Use Files (PUFs)<sup>25</sup>.
- 2016**  
In 2016 the U.S. Supreme Court ruling in *Gobeille v. Liberty Mutual*<sup>26</sup> that states cannot compel self-insured plans regulated by ERISA (Employee Retirement Income Security Act of 1974) to submit their data to State APCDs resulted in a loss of a significant amount of ERISA self-funded plan data in APCDs. This has impacted the ability of State APCD data users to fully understand the health care marketplace and its population. Some states have had success in the voluntary submission of these data, and efforts are underway at the federal level to further encourage participation.
- 2020**  
The MN APCD includes health care transaction data, or claims, for over 4.6 million people, as of 2020, covering more than 10 years of health care use in the state. Data are collected for over 95% of individuals with Medicare and those who rely on Minnesota Health Care Programs as well as over 40% of the commercially insured population.



<sup>24</sup> Minnesota Statutes. (2008). *62u.04 payment reform; health care costs; quality outcomes*. Office of the Revisor of Statutes. <https://www.revisor.mn.gov/statutes/cite/62U.04>

<sup>25</sup> [Currently Available Public Use Files \(state.mn.us\)](https://www.mn.gov/Currently-Available-Public-Use-Files)

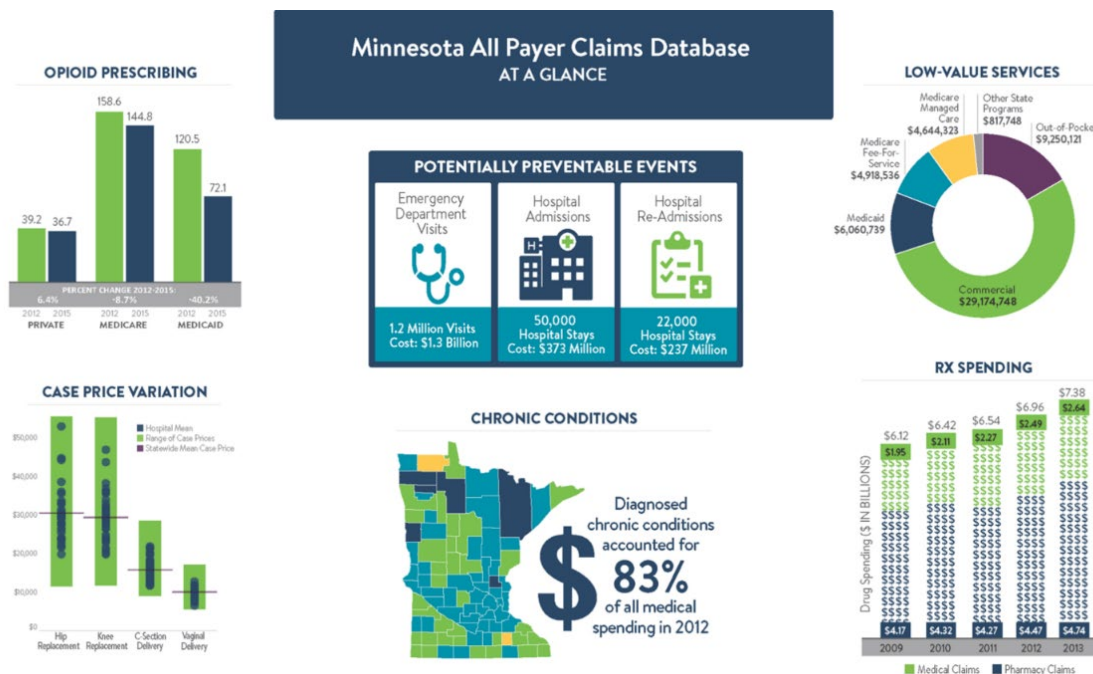
<sup>26</sup> <https://www.apcdouncil.org/scotus-gobeille-v-liberty-mutual-insurance-company-decision>

## 2022

Today, Minnesota is a leader in the use of APCD data to study health related issues across a wide spectrum of applications, ranging from public health to health care markets and pricing, to assessing trends in prescription drug use and cost. Data in the PUFs are formatted in spreadsheets and are now available in user-friendly dashboards<sup>27</sup>, with aggregated records that prevent the identification of individual members, providers, and health plans.

To date, MDH has used the MN APCD for a wide range of applied research studies that fall into the following broad categories: Health care utilization and spending, health care quality, system efficiency and waste, health care market, epidemiology, and public health. These research studies align within the permitted uses of the MN APCD set forth by the Minnesota Legislature, which includes legislative-directed studies as well as studies of variation (including geographic variation) in utilization, cost, quality, and illness burden.<sup>28</sup> Highlights from some of these studies are shown in the Figure below. A list of all completed studies using the MN APCD is available on MDH website.<sup>29</sup> Examples of these topics include children’s health care, spending among high cost-high need individuals, spending on primary care, telemedicine, utilization, and spending for prescription drugs.

Figure 3A. MN APCD — At A Glance



<sup>27</sup> [www.health.state.mn.us/data/apcd/publicusefiles/dashboards/index.html](http://www.health.state.mn.us/data/apcd/publicusefiles/dashboards/index.html)

<sup>28</sup> Authorized uses of the data were initially limited to a 2-year window. The Legislature has extended the sunset now several times. Without further action by the Legislature, authorized use of the MN APCD would conclude on July 1, 2023.

<sup>29</sup> <https://www.health.state.mn.us/data/apcd/publications.html>

The MN APCD, like most other APCDs, does not include data from uninsured Minnesotans or those whose care is covered by Tricare, Veterans Affairs benefits, or the Indian Health Service. In addition, the MN APCD does not include claims from plans that do not cover general medical care, such as dental-only insurance, workers' compensation, and accident-only insurance.

Data in the MN APCD are de-identified, which means the data do not include individually identifiable elements, such as name, address, social security number, or birth date. This is unlike most other state APCDs which do collect identifiable information, but then de-identify for use. The benefit of collecting individually identifiable elements is that doing so allows states to better link individuals within and across health plans and over time. It also allows for opportunities to link with other datasets, allowing researchers and policy makers to better understand health care trends and create a more comprehensive picture of health of a community across disparate systems.

In addition, MN's current scope of data collection limit's data user's ability to fully assess health care cost, quality, access, and burden. For example:

- Lack of dental claims data creates a gap in a key aspect of health and well-being from scrutiny.
- The absence of non-claims-based data means that a certain (unknown) volume of spending on incentive payments or contract settlements isn't systematically monitored.
- The limits on available demographic information inhibits data quality checks and the ability to disaggregate the data in meaningful ways to better understand issues of health equity
- The restriction of publishing provider organization names or individual providers limit transparency efforts that allow consumers to compare costs by health care facilities.

MDH is currently the only legislatively authorized direct user of the MN APCD, which is unlike every other APCD in the country. Operating under the current provisions access to the data is limited for outside entities. Other states have authorized a broader set of users and use cases both within and external to the state. As a result of these limitations, the researchers, policy makers, and the public only has access to the information that MDH produces.

MDH has demonstrated the ability to successfully protect and manage the MN APCD for their use cases but restrictions on its use has limited what Minnesota can gain from the MN APCD. Unlike other states, MDH has not had the ability to support health insurance rate review, evaluate the relative effectiveness of health technology, or conduct clinical studies on the effectiveness of alternative therapies.

The narrow set of permitted use cases and limitations on collected and identifiable data elements has impacted data quality, limited the ability to use the data for transparency efforts, and confined the understanding of broad health trends. The recommendations put forward in this report for expanded access, collection, and use of the MN APCD intend to diminish these limitations while continuing to ensure security and protect privacy.



## PROCESS FOR DEVELOPING RECOMMENDATIONS

For the development of these recommendations to expand access, collection, and use of the MN APCD, MDH partnered with HSRI. HSRI’s Population Health Team has over 20 years of experience building data systems to collect, analyze, and report health care data to improve the quality of health information available for research, policy, and practice. The team’s extensive experience with APCDs, data release policies, and operations in other states, including Maine, Colorado, Oregon, and New Hampshire, provides a strong foundation to inform recommendations in Minnesota.

This final recommendation report highlights the results of a year-long process. This process included a preliminary report with initial findings, a comprehensive review of APCDs in other states that resulted in a summary of best practices, and engagement with a variety of stakeholders in Minnesota who could benefit from expanded access and use of the MN APCD.

**Figure 4A. Recommendation Report Process**



## Appendix B: Environmental Scan of Best Practices

### OVERVIEW

HSRI conducted an environmental scan of other state APCDs to develop best practices to support the recommendations for expansion of the MN APCD. The environmental scan included evaluating existing data release policies and practices of well-regarded state APCDs, along with federal agencies – such as the Centers for Medicare & Medicaid Services (CMS) – to examine the viewpoints of agencies releasing data and from potential data users, both internal and external to the state agency, and determine how systems at the state and national level can inform and add value to the recommendations for Minnesota.

To help inform the final recommendations in this report, the Environmental Scan looked at seven key areas from the 17 existing APCDs in the country:

1. State Agency Use of APCDs
2. Policy Language for Data Sharing
3. De-identification and Aggregation Requirements
4. Application and Agreements to Access and Use Data
5. Process for Data Access/Release
6. Cost Implications
7. Communication

The following are high-level findings from the Environmental Scan:

- All state APCDs, except for Minnesota, have data use policies to share granular data with authorized users for a range of uses. Approximately 50% of states produce PUFs, though not all are as robust as Minnesota, while about 25% share public use data files that are not consumer friendly but rather an option for a data-savvy user.
- Clear and robust data governance provisions for oversight of data and data users' compliance with data use provisions is a critical element to a successful data use policy.
- A data release committee is a key component of a successful oversight process, 90% of state APCDs utilize a review committee as part of their governance process.
- Adoption of expanded access and use of APCD data policies can coexist with robust data protections and patient privacy provisions.
- To serve a broad set of data users, many states have enhanced their data by collecting additional information. More than 50% of all state APCDs collect dental claims while only about 25% collect non-claims-based payments. The inclusion of these data appears to be an emerging trend since the collection of these data is a more recent addition for many states.
- State-university partnerships can be effective tools to maximize the effectiveness of data for policy applications, 30% of state APCDs discussed their partnership with a university in their state with Minnesota during the research phase of this project though more may have similar partnerships.

- Expanded use requires additional resources to cover costs associated with the collection, management, and sharing of these data.

## FINAL DELIVERABLE: STATE APCD ENVIRONMENTAL SCAN OF BEST PRACTICES

This State APCD Environmental Scan of Best Practices is part of a broader Recommendation Report that Human Services Research Institute (HSRI) has prepared to support expanded use and access of the Minnesota APCD. As Minnesota considers this expansion, it is important to consider what could be learned from other states and federal agencies from two viewpoints: agency releasing data and potential data users, both state agency and external users.

State APCDs are run in a variety of ways in states; some are housed within the Department of Health, like in Minnesota; some are run through appointed administrators, like Colorado; while others have shared responsibility between a state's Medicaid office and Department of Insurance, like New Hampshire. Since no two states are set up the same way, the framework and policies for data sharing are set up differently in each state, though use cases, legislative language and experiences are valuable to review. When looking across states, it can be helpful to understand which states are comparable to Minnesota in terms of population size, the number of data submitters, and states with similar privacy protection requirements. Oregon is similar in population size and the number of data submitters, and while Arkansas is smaller in size, it had similar deidentification requirements during the data collection process.

First, this report will provide an overview of uses of APCD data by state agencies, and how these uses benefit states and other stakeholders. Second, it will review language used in states' statutes and rules, and how that language supports the release and use of data in those states, including de-identification and aggregation requirements. Finally, to highlight key considerations for Minnesota, this report includes details on data sharing processes and communication practices among state APCDs.

### State Agency Use of APCD

The use of APCD by state agencies varies across states, though many have commonalities — such as using data to improve price transparency and the use of data for balance billing resolution since claims data present actual costs for most payers and providers in a state. Public health is another area that APCD data is used frequently, while states like Maine are pushing the boundaries with prescription drug reports.<sup>30</sup>

#### *Insurance Departments*

Departments of Insurance<sup>31</sup> have been using APCD data to reduce the reporting burden for insurance carriers, to better understand the marketplace and help minimize the rise in premiums or even lower the cost. The National

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<sup>30</sup> <http://mhdo.maine.gov/tableau/prescriptionreports/cshtml>

<sup>31</sup> [https://www.manatt.com/Manatt/media/Media/Images/Rectangle/APCD\\_Enhancing-the-Value-of-Coverage-Through-Transparency-November-2018\\_e.pdf](https://www.manatt.com/Manatt/media/Media/Images/Rectangle/APCD_Enhancing-the-Value-of-Coverage-Through-Transparency-November-2018_e.pdf)

Association of Insurance Commissioners supports the use of APCD data in insurance regulation and the projects that have come out of states using the data.

- Massachusetts uses APCD to regularly monitor commercial enrollment trends, eliminating select payer reporting to the Department of Insurance.
- Oregon has used its APCD to track primary care spending trends in the commercial insurance markets.
- The Arkansas Insurance Department uses the APCD in its regulatory function with network adequacy and rate reviews.
- New Hampshire redesigned its Network Adequacy with an innovative reporting rule, minimizing reporting to the department by health insurance carriers and setting standards for adequacy based on real patient experiences using its APCD. The new network adequacy standards support the use of lower cost providers for minimum network standard.
- The Colorado Department of Insurance uses data from its state's APCD to analyze medical and pharmacy costs trends to provide background for insurer rate setting and to identify county level cost drivers.

Price Transparency is a popular concept for reducing the cost of health care,<sup>32</sup> much like the other efforts by Insurance Departments. When consumers and providers better understand the cost of services ahead of use, better choices can be made to help drive down costs. Health care transparency has been found as a lever that can be used to lower health care costs and a resource that is welcomed by consumers. Though there is often pushback from payers and providers initially, there have been many notable instances in which both stakeholders have benefitted from transparency.

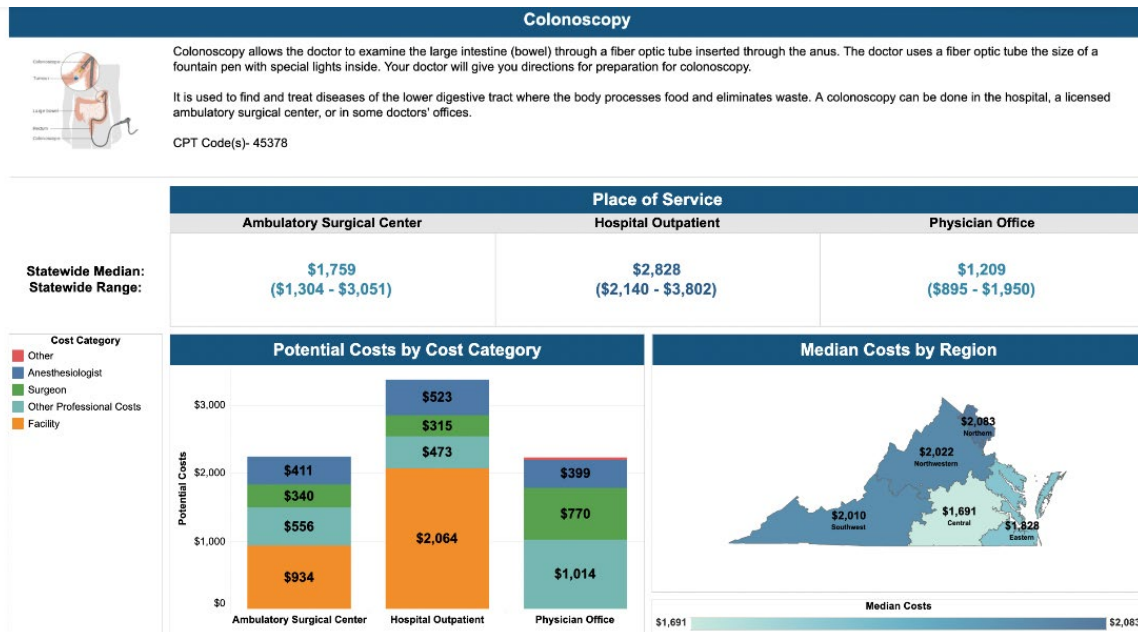
Virginia's new price transparency tool<sup>33</sup> provides insight into the variation in cost in the state while not sharing estimates by provider:

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<sup>32</sup> [http://www-personal.umich.edu/~zachb/zbrown\\_eqm\\_effects\\_price\\_transparency.pdf](http://www-personal.umich.edu/~zachb/zbrown_eqm_effects_price_transparency.pdf)

<sup>33</sup> <https://www.vhi.org/HealthcarePricing/default.asp>

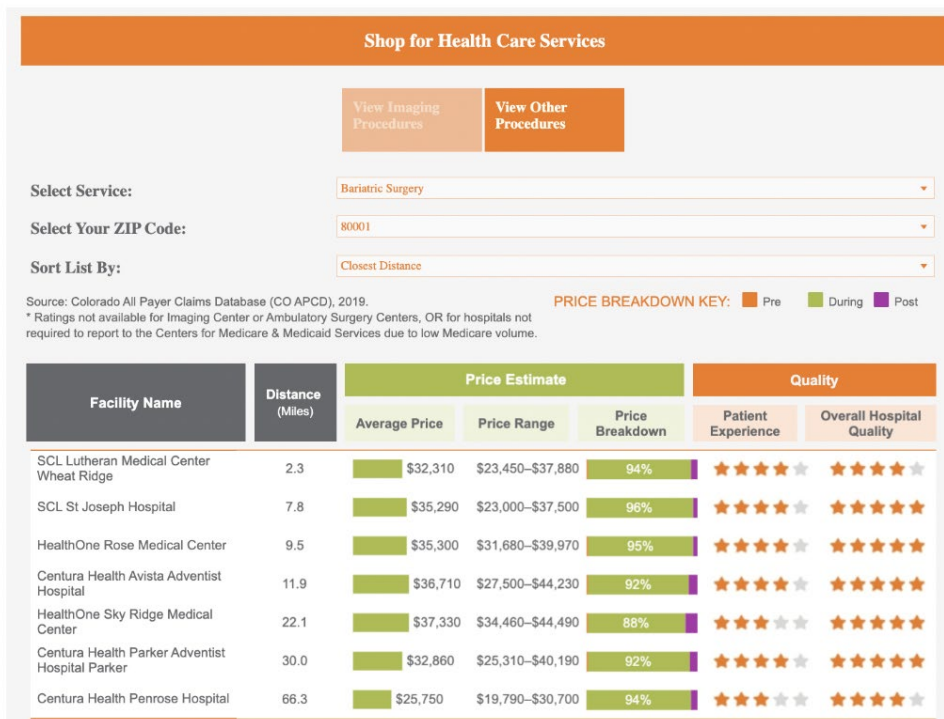
Image 1C. Virginia Price Transparency Tool



Colorado uses a similar Tableau dashboard interface to Virginia but provides much more granular information on cost in the state:

Image 2C. CIVHC Shop for Care Tool

## Shop For Care



## *Medicaid*

Medicaid offices in almost all states with an APCD have benefitted from the use of the data in a variety of ways, saving the states time and money. Data are used by the Medicaid offices in the contracting process to determine appropriate Medicaid reimbursement rates. Some states have used the data to drill into more specific topics related to Medicaid spending, often through legislative request:

- Emergency department utilization
  - Generally, and for mental health crises
  - Dental emergencies
- Trends in teen pregnancy
- Utilization and cost of substance use disorder (SUD) services
- COVID-19 related dashboards including vaccinations, hospitalizations, etc.
- Gaining a better understanding of the current and anticipated Medicaid expansion population by generating a profile of newly eligible members based on demographics, likely health conditions, service needs, critical events, and anticipated costs

## *Health Departments*

Departments of health like in Minnesota have used APCD for a wide variety of studies often in response to legislative inquiry. Other examples include:

- Utah's Department of Health's<sup>34</sup> report on flu vaccine trends in December 2020
- The Maine HHS Office of Behavioral Health's (OBH) use of claims to investigate and quantify the impact of COVID-19 restrictions have had on access to and utilization of behavioral health care services in Maine

Outside data users have also employed state APCD to study areas of public health interest. Examples include:

- New England Public Policy Center's<sup>35</sup> study on the efficacy of opioid abuse treatment in the state of Rhode Island
- In 2021, the Journal of the American College of Radiology<sup>36</sup> use of data from the Colorado APCD to study determinants' effects of longitudinal adherence to lung cancer screenings
- University of Southern Maine's use of data to assess maternal health care utilization and morbidity in the first 24 months' postpartum among women in Maine

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<sup>34</sup> <https://stats.health.utah.gov/publications/databytes/databyte-flu-vaccination-trends/>

<sup>35</sup> <https://www.bostonfed.org/news-and-events/news/2021/01/addressing-rhode-island-opioid-crisis-neppc.aspx>

<sup>36</sup> [https://www.jacr.org/article/S1546-1440\(21\)00225-8/fulltext](https://www.jacr.org/article/S1546-1440(21)00225-8/fulltext)

## *Department of Justice*

Though not widely used in Departments of Justice (DOJ), APCD data can be a valuable tool for antitrust and provider consolidation considerations and reviews. The New Hampshire DOJ used its state's APCD to determine if hospital mergers would violate the state's antitrust laws and, while consolidations were deemed lawful, the use of data provided the DOJ with valuable insight into the potential impacts to consumers when considering cost and access to care.

## **Policy Language for Data Sharing**

When considering expanded use of APCD data it is important to look at how states have established policies related to data sharing whether it is cautious or more aggressive. The policy choice impacts the process, so it is the best place to start the environmental scan.

## *State Perspective*

The language used in the statutes and rules vary as much as the states themselves but most express a desire for data use to benefit their state, inform on health policy, and improve health care choices. Some states prefer to have language in statute or rule that includes some specifics, such as makeup of review committees, fees for use of data, and requirements for HIPAA privacy compliance.

Language regarding clear purpose and intention for sharing data is found across state statutes. Examples of simple language that convey the state's interest in making the data available can be found in states like Arkansas<sup>37</sup> and New Hampshire<sup>38</sup>; both state's statutes indicate that secure data (with privacy protections) can be a valuable resource for health care decisions among consumers, researchers, and policymakers. Statutes in Washington<sup>39</sup> and Oregon<sup>40</sup> (section 442.373) include language much more detailed about data use and availability specific to the data user, as well as the limitations of data use for privacy protections.

Federal data sharing also relies on clear policy language to limit access to those who will use the data properly and for the intended purposes. Whether it is regarding who<sup>41</sup> may use or how<sup>42</sup> they may use data from CMS, the policy language is clearly articulated on the website.

## *Data User/Requester Perspective*

A state APCD that has language in statute or rule that clarifies parameters for data use builds confidence among potential research applicants. Statutes, as seen in Arkansas, that restrict data access "for legitimate research

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<sup>37</sup> <https://www.arkleg.state.ar.us/Acts/Document?type=pdf&act=1233&ddBienniumSession=2015%2F2015R>

<sup>38</sup> <http://www.gencourt.state.nh.us/rsa/html/XXXVII/420-G/420-G-11-a.htm>

<sup>39</sup> <https://app.leg.wa.gov/RCW/default.aspx?cite=43.371.050>

<sup>40</sup> [https://www.oregonlegislature.gov/bills\\_laws/ors/ors442.html](https://www.oregonlegislature.gov/bills_laws/ors/ors442.html)

<sup>41</sup> <https://resdac.org/articles/cms-non-us-based-researcher-policy#:~:text=Non%2DUS%20based%20researchers%20are,are%20temporarily%20in%20another%20country>

<sup>42</sup> <http://resdac.org/articles/cms-cell-size-suppression-policy>

purposes to qualified researchers,”<sup>43</sup> helps to dissuade those interested in requesting data to use it for profit and not research.

Language in statute or rule typically includes details specific to a data user’s ability to produce and publish work. Clear expectations and understanding for both state and data user on how states will review findings is crucial and prevents disagreements. Having the ability to share concerns prior to the start of any research should be built into the process. Example language: “a written statement to the researcher stating specifically the problematic sections in the publication and the expectations for edits.”

## Deidentification and Aggregation Requirements

Variations in privacy requirements across states make this topic an important one to consider to better understand how states address privacy protection and adherence to the HIPAA privacy rule when reports are released.

### *State Perspective*

Not all states collect data with the personal identifiers hashed or encrypted like Minnesota does. Only Arkansas and New Hampshire have similar requirements for privacy protection when the data are received into the APCD. States that collect data with individuals identified also include deidentification policies into their data release since almost all extracts of data are released using the safe harbor method<sup>44</sup> of privacy, as recommended through the HIPAA privacy rule. Data released without deidentification requires additional scrutiny in the application review process and safeguards for use of the data. This is the case in Oregon, which considers such a request a Custom Data Set:

*“Direct identifiers such as patient name or address are only released in compliance with HIPAA requirements and may require specific approvals such as patient consent and review by an Institutional Review Board (IRB) and/or Oregon’s Department of Justice (DOJ). Custom data sets can be linked to other external data sets, as long as this is explicitly approved by the Oregon Health Authority (OHA).”*

Most states release data outside their APCD to state agencies and qualified researchers with the capacity and ability to properly analyze the data. Data released outside of state agencies is typically a limited data set, which is a data set that is stripped of certain direct identifiers. The purpose of the external data release is typically for research, public health, or health care operations purposes.

### *Data User/Requester Perspective*

Some states have data aggregation requirements beyond safe harbor and expert determination as stipulated in HIPAA privacy rule. It is important that this is known to a potential data user as they consider use of data for a

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<sup>43</sup> <https://www.arkleg.state.ar.us/Acts/Document?type=pdf&act=1233&ddBienniumSession=2015%2F2015R>

<sup>44</sup> <https://www.hhs.gov/hipaa/for-professionals/privacy/special-topics/de-identification/index.html>



study. Some states choose to highlight the key components of privacy compliance in their data release documentation.

1. Additional language is often included to explicitly state that constructive reidentification of individuals is prohibited in any way.
2. Limitations on provider/payer specific details.
  - a. Example: Virginia “Does not disclose or report provider-specific, facility-specific, or carrier-specific reimbursement information, or information capable of being reverse-engineered, combined, or otherwise used to calculate or derive such reimbursement information, from the All-Payer Claims Database”<sup>45</sup>

## Application and Agreements to Access and Use Data

The qualification to apply for data use and the agreements that a user is required to sign are not uniform across state APCDs, though there are many commonalities.

### *State Perspective*

State application requirements often include a description of who is considered a qualified applicant, like in New Hampshire:

*“The qualifications of the investigator and research staff demonstrate their ability to undertake the study or accomplish the intended study as documented by training and previous research, including prior publications in the proposed or related area; and an affiliation with a university, private research organization, medical center, state agency, or other institution that will provide sufficient research resources.”<sup>46</sup>*

Many states limit data release to state agencies and those using data for true research and there is language in statute or rule that reads “limited use data sets shall only be released for purposes of research,” for example.

A Data Use Agreement (DUA) is a key element in data release of any protected data set including APCD. A DUA is an agreement that must be entered into *before* there is any use or disclosure of a limited data set to an outside institution or party. DUAs are fairly standard across state APCDs and, as noted in the California report<sup>47</sup>, DUAs share virtually the same requirements.

Data use agreements utilized by other state APCDs share many commonalities that protect the privacy of those in the data as well as the organization sharing the data. The table below was created by the Rand Corporation when they completed a review of DUA’s across the country.<sup>48</sup>

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<sup>45</sup> <https://lis.virginia.gov/cgi-bin/legp604.exe?191CfulCCHAP0672>

<sup>46</sup> [https://gencourt.state.nh.us/rules/state\\_agencies/he-w900.html](https://gencourt.state.nh.us/rules/state_agencies/he-w900.html)

<sup>47</sup> HPD Legislative Report. (ca.gov). <https://hcai.ca.gov/wp-content/uploads/2020/12/HPD-Legislative-Report-20200306.pdf>

<sup>48</sup> Gudiksen, K., Chang, S.M., & King, J.S. (2019). The Secret of Health Care Prices: Why Transparency is in the Public Interest. <https://www.chcf.org/wp-content/uploads/2019/06/SecretHealthCarePrices.pdf>

**Table 1C. Common Elements in DUAs Among Active APCDs**

Elements	AR	CO	DE	FL	ME	MA	NH	RI	UT	VT	WA
APCD retains ownership			X	X	X	X		X	X	X	X
Certificate of data destruction	X	X	X		X	X	X	X	X	X	X
Data management plan / Requirement of safeguards	X	X	X	X	X	X	X	X	X	X	X
Data only to be used as described in application	X	X	X	X	X	X	X		X	X	X
Indemnification	X	X	X	X	X	X	X	X	X		X
Prohibition of disclosure (of reports or data) without prior notice	X	X	X	X	X	X	X	X	X	X	X
Prohibition on identification of patients (including reverse engineering)	X	X	X	X	X	X	X	X		X	X

The following is additional information about the DUA Elements:

- **APCD retains data ownership:** The APCD remains the owner of data assets and manages policies regarding the acquisition, use and distribution of the data in any form.
- **Certificate of data destruction:** A formal document stating that digital media has been destroyed.
- **Data management plan:** A plan detailed by the data owner and a requisite of data access and includes safeguards for security, access, and privacy.
- **Data only to be used as described in application:** A data user describes their intended use of data in the application process and agrees to limit the use of data to that narrow scope in the DUA. Any additional use or findings from the use of the data would be considered a violation of the DUA.
- **Indemnification:** A clause in the DUA, also known as a hold harmless provision, that set out to protect the state APCD from liability if a data user or third entity is harmed in any way or losses incurred through the contract and protects the state APCD from any liability associated with a data users use of the data.
- **Prohibition of disclosure (of reports or data) without prior notice:** The DUA includes a requirement for a data user to disclose to the state APCD its intention to publish or disclose report or findings and agreement that the report or findings is in alignment with the terms of the DUA.
- **Prohibition on identification of patients (including reverse engineering):** The DUA includes a provision that prohibits a user from identifying a person in the data including any kind of constructive re-identification of a person in the data whose PII is protected with encryption or hashing.

## *Data User/Requester Perspective*

Data use agreements, which are often publicly available, provide the data user with clear, specific parameters of use to increase the likelihood of DUA compliance. DUA language that outside data users might encounter include the following example from Colorado:

1. Limits on use of data, including who may have access to the data as named in the data use application.
2. Repercussions for misuse of data:
  - a. “Violation of the terms of the Data Use Agreement constitutes a breach of contract and may:
3. Require immediate surrender and return of all APCD data.
4. Result in denial of future access to APCD data.
5. Lead to civil action by the Administrator for breach of contract.
6. Result in a complaint filed with the U. S. Department of Health & Human Services, Office for Civil Rights, as well as civil and criminal action and penalties.
7. State Attorneys General are also empowered under the HITECH Act to take civil action regarding certain HIPAA violations.”<sup>49</sup>
8. Requirements for data destruction, including certification proving completion.
9. State expectations for sharing findings and if the state can prevent use or require edits. Sample language to specify expectations might be included in rule and DUA:
  - a. “The researcher shall provide the department with a copy of any proposed release at least XX days prior to publication or release of any report or publication that contains information derived from the data set so that the department can review the release and verify that the agreed upon conditions have been applied.
  - b. If the department determines that a report or publication contains information that might lead to direct or indirect identification of patients, employers or other group purchasers, the department shall provide a written statement to the researcher stating specifically the problematic sections in the publication.”

## **Process for Data Access/Release**

Once a state has determined who may apply for and access the data, the process to implement those policies is also different among states. Some states make it easier for state agencies than outsiders while others try to keep the process transparent since there are often questions and time sensitivity to requests for data.

## *State Perspective*

State approaches to data release policies vary but there is value in having clear policies, especially if they differ for an in-state university data user or agency versus an outside data user. A state may want to facilitate a permanent solution for data users within the state that establishes an agreement to terms and conditions for a

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<sup>49</sup> Colorado APCD Data Release FAQ <http://www.civhc.org/wp-content/uploads/2017/08/Data-Release-Info-Guide-2-24.13.pdf>

long-term relationship with the APCD; this could help eliminate the need to include their projects in the data request and review process.

State APCDs share data with state agencies in very different ways. Included below are highlights:

- New Hampshire's statute names the specific agencies that use the APCD; those agencies share the cost of the project and details of data use are agreed to in a Memorandum of Understanding (MOU) or Interagency Agreement (IAA).
- Colorado has agency-specific solutions for use of data, using subscription-based access to data with Medicaid Match dollars shared, pay-by-project, and fiscal notes to cover costs.
- Oregon requires state agencies to apply for data use like all other requestors, though costs are often reduced or waived.

University users in a state may be covered by a master agreement for use that is broader than one intended for other research institutions, but often still requires approval for specific case studies that use the data.

For a data requestor that is not covered by an in-state agreement, publicly available step-by-step instructions on the data application requirements, timeline for processing applications (especially if a review committee is involved), and duration of use, again, reduces the administrative burden on staff.

The state of Arkansas created the following infographic that covers each step of the application process and displays it clearly on their website:

**Image 3C. Arkansas Data Request Process**

## ARKANSAS HTI DATA REQUEST PROCESS

The Arkansas HTI is now available for data requests through the Arkansas Center for Health Improvement (ACHI), the statutorily named administrator. The steps below will guide the requester through the process to request and receive data output. Currently, only datasets can be requested from the Arkansas HTI. Reports, analytics, counts, and data output that require custom data aggregation are not available at this time.

<b>1</b>	<b>DATA REQUESTER SUBMITS DATA REQUEST</b>	The data requester submits a data request form and data element list. This allows ACHI to ask additional questions and determine feasibility of the request.
<b>2</b>	<b>ACHI WORKS WITH DATA REQUESTER</b>	ACHI determines counts, identifies aggregation requirements (if applicable), and allows the data requester to make changes to the data request before initiating the approval process. A price estimate may be given at this time.
<b>3</b>	<b>DATA REQUESTER COMPLETES DATA REQUEST</b>	The completed data request includes a data management plan, in addition to the data request form and data element list. Data requests are reviewed based on the <a href="#">Arkansas HTI Data Request Monthly Review Schedule</a> . A final price for the data will be provided.
<b>4</b>	<b>DATA OVERSIGHT COMMITTEE REVIEWS</b>	The committee reviews completed data requests. The committee may refer the data request to the Scientific Advisory Committee for academic research. The committee offers a recommendation to the Healthcare Transparency Initiative Board.
<b>5</b>	<b>HEALTHCARE TRANSPARENCY INITIATIVE BOARD REVIEWS</b>	The board reviews data requests on a quarterly basis and makes final recommendations to the Arkansas insurance commissioner. The board may recommend approval to provide access, may recommend approval subject to conditions or modifications, or may deny the request.
<b>6</b>	<b>ARKANSAS INSURANCE COMMISSIONER MAKES DECISION ON DATA REQUEST</b>	The Arkansas insurance commissioner may approve or deny data requests in whole or in part.
<b>7</b>	<b>HEALTHCARE TRANSPARENCY INITIATIVE BOARD REVIEWS</b>	Data request fulfillment begins after a data use agreement is signed with the Arkansas Insurance Department and a project plan is finalized. A <a href="#">Certification of Project Completion &amp; Destruction or Retention of Data</a> form must be completed at the end of the project term.

### *Data Release Review Committee*

A data release review committee is a part of most states’ data release process. The composition of the committee is often explicitly stated in statute or rule and includes key stakeholders but vary in size and scope across states.

One of the smaller committees is New Hampshire’s, detailed in its data release rule HE-W900:

1. One member representing insurance carriers
2. One member representing health care facilities
3. One member representing health care practitioners
4. One member representing the general public
5. One member representing purchasers of health insurance

6. One member representing health care researchers
7. Two members of the department

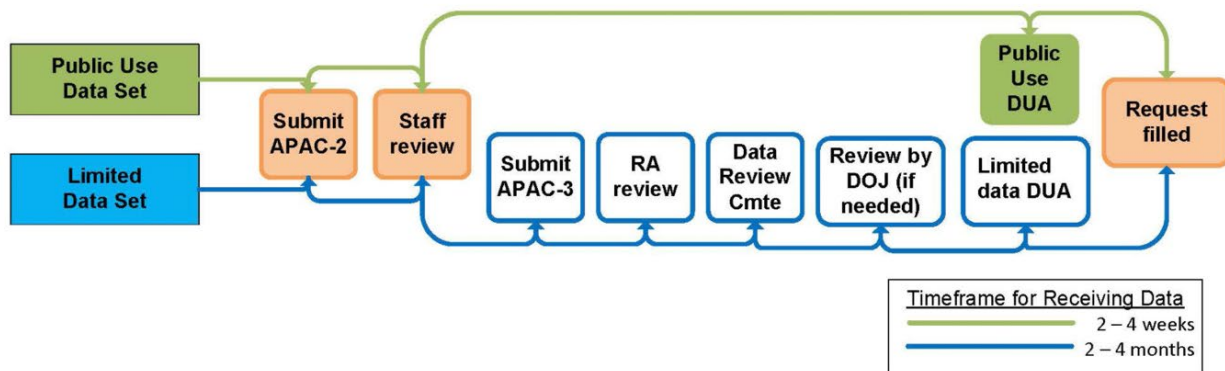
In Colorado, there is a clear policies and procedures document<sup>50</sup> available to provide the committee with information on what the committee is to review and how they review the applications. Transparency on the considerations of the committee will also help a data requestor determine if their request is valid and what to expect from the review process, thus reducing the burden on the agency that would otherwise be asked to explain the process.

### Data User/Requester Perspective

A clear and simple timeline helps keep the committee on schedule and provides a researcher with a timetable that is useful for project management. Oregon created a simple yet effective infographic that describes the steps and timeline from application submission to receipt of data for an approved user:

Image 4C. Oregon Data Access Timeline

#### How to Obtain APAC Data

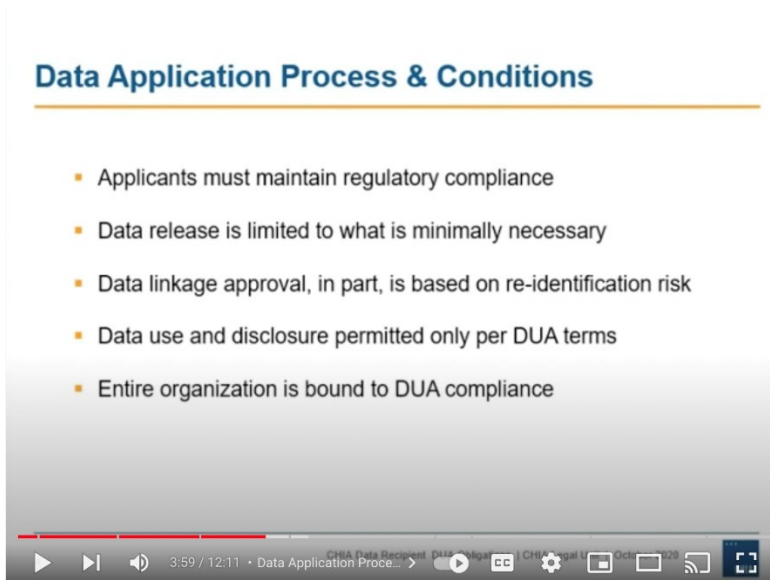


Massachusetts includes a video<sup>51</sup> on its application page clarifying expectations on data use and the application process:

<sup>50</sup> <http://www.civhc.org/wp-content/uploads/2017/08/CIVHC-DRRC-Policies-and-Procedures-2-3-12.pdf>

<sup>51</sup> <https://www.youtube.com/watch?v=Zr0GTm9PBXg>

**Image 5C. Massachusetts Data Application Video Screenshot**



The role of the review committee and how much influence these stakeholders have on data release can be a mystery to data requestors. Including details about the committee’s role and responsibility will help a data submitter better understand the application process and assure researchers and other stakeholders that there is integrity in the process.

Colorado has a thorough FAQ section on their APCD website<sup>52</sup> that provides an easy-to-follow Q&A approach to details on the data release process:

“The CO APCD Governance Rules<sup>53</sup> promulgated by the Department of Health Care Policy and Finance (HCPF) require that the Data Release Review Committee (DRRC) develop protocols for the release of CO APCD data. The DRRC is comprised of health care data and analytical experts representing a variety of organizations and stakeholder perspectives. The rules require that the DRRC review all requests and advise CIVHC on whether release of the data is consistent with the statutory purpose of the CO APCD, will contribute to efforts to improve health care for Colorado residents, complies with the requirements of HIPAA and will employ appropriate analytical methods.”

Washington includes a public comment period,<sup>54</sup> and their release committee, like other states: “Requests that include the release of PHI or PFI require a 15-day public comment period and review by the Data Release Advisory Committee (DRAC). The committee reviews each request for compliance with law, including establishing that the data sought is the minimum amount necessary to achieve a specific purpose and establishing that the requested data elements are adequate and appropriate.”

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<sup>52</sup> <https://www.civhc.org/co-apcd-data-user-resources/>

<sup>53</sup> <https://www.civhc.org/knowledgebase/who-decides-who-can-get-information-from-the-co-apcd-what-rules-do-they-use/>

<sup>54</sup> <https://www.hca.wa.gov/about-hca/washington-state-all-payer-claims-database-wa-apcd>

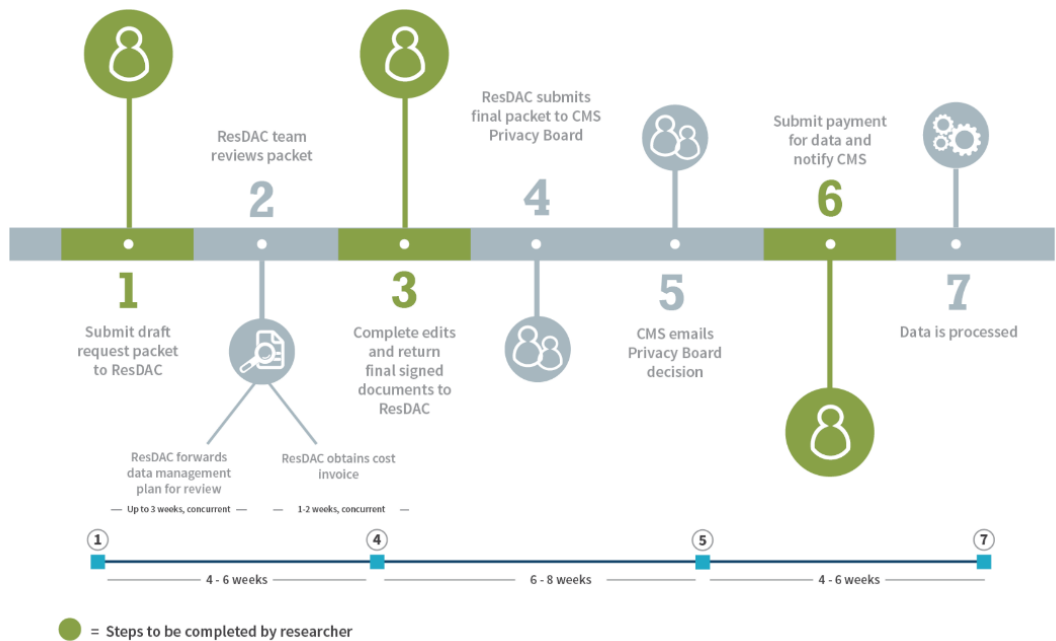
The duration of the comment period varies from 10 days in Rhode Island to 30 days in Maine.

CMS has a comprehensive website for data requests. Due to the high volume of requests, CMS has hired the University of Minnesota to run the Research Data Assistance Center (ResDAC). Included on the ResDAC site is a flow chart illustrating the process and requisite steps for the researcher. While the process may be complicated and time consuming, a simple flow chart helps to eliminate some confusion and correspondence with the data release team.

**Image 6C. ResDAC Flow Chart for Data Requests**

The flowchart illustrates the steps in the process to request CMS identifiable data and the involvement of each organization in the process.

You will need to submit a research request packet that includes a description of the research being conducted along with other materials. The [Request Materials Tool](#) will help you determine the documents you need. To begin the request process, email a draft (no signatures) of the documents in their original format (.xls, .pdf, .doc) to [resdac@umn.edu](mailto:resdac@umn.edu).



**Cost Implications**

Expanded use of APCD data requires use of additional resources. States often rely on fee structures to offset the cost of the resources expended reviewing applications, creating access to data, or producing reports.

*State Perspective*

Expanding the use of APCD data by sharing with other users outside of the APCD agency increases the burden on existing resources within the agency and may require additional resources to meet the needs associated. Many states rely on a fee structure to cover the costs, others help to fund the APCD with their fees and one state covers all of the cost of data release.

The following table attempts to put the variations in cost into a uniform view to compare. Most states have a variety of options so not all options in each state are included:



**Table 2C. Fee Structures**

State	Cost per single year Extract (all files)	Cost per multiyear Extract (all files)	Report Cost	Subscription Cost	Scholarship availability	Application Fee
Arkansas	\$11,000-\$15,000	\$17,000-\$65,000	N/A	\$200,000-\$300,000	Yes	
Colorado	N/A	\$13,000+	\$500-\$1500+		Yes	
Maine	\$8,000-\$11,500*		\$80/hour			
Massachusetts		\$13,000-\$40,000	\$140/hour		Yes	\$300
Minnesota	N/A	N/A	N/A	N/A	N/A	
NH	\$0	\$0	N/A	N/A	N/A	\$0
Rhode Island		\$25,000-\$87,500				\$100
Oregon	\$2,000-\$10,000	Depends on time and request				
Utah	\$8,000-\$20,000	\$12,000-\$40,000+			Yes	\$50
Washington			\$7,000-\$17,500	\$40,000-\$100,000*		

### Medicaid Match Funding

A benefit of sharing data and/or data findings with the state Medicaid agency is the ability to qualify for Medicaid match funding. While it may be a time-consuming process to apply for the funding, which must be done through the Medicaid office, most state APCDs receive funding and the Medicaid office receives the benefit of the insights of the comprehensive data.

Medicaid Financial Federal Participation (FFP) requires advanced planning documents, and all requests must come from the state Medicaid Agency. States have applied for and been granted matching funds in two ways<sup>55</sup>:

<sup>55</sup> [https://www.ssa.gov/OP\\_Home/ssact/title19/1903.htm](https://www.ssa.gov/OP_Home/ssact/title19/1903.htm)

1. Administrative Match (50/50) Soc. Sec. Act Sec. 1903(a)(7) — Medicaid matches 50% of costs (an amount equal to 50 per centum of the remainder of the amounts expended during such quarter as found necessary by the Secretary for the proper and efficient administration of the State plan).
2. Enhanced Match (90/10) Soc. Sec. Act Sec. 1903(a)(3) — otherwise referred to as 90/10 funds. (90 per centum of so much of the sums expended during such quarter as are attributable to the design, development, or installation of such mechanized claims processing and information retrieval systems as the Secretary determines are likely to provide more efficient, economical, and effective administration of the plan and to be compatible with the claims processing and information retrieval systems utilized in the administration of Title XVIII, including the State’s share of the cost of installing such a system to be used jointly in the administration of such State’s plan and the plan of any other State approved under this title.<sup>56</sup>

States whose APCD is not part of its Medicaid agency have created partnerships or working relationships so that the data can be of benefit to the Medicaid’s agency’s work and the APCD can be eligible to receive some of the Medicaid Match dollars the agency may receive.

- New Hampshire’s Medicaid agency is a partner on the state’s APCD and qualified to use the enhanced match funds for a portion of the cost of the APCD that is focused on Medicaid.
- Colorado and Oregon APCDs receive funding through both the enhanced and administrative match funds from their state’s Medicaid agency.
- Utah’s APCD agency has received administrative match funding that is based on the percent of Medicaid members in the state’s APCD.

States shared a variety of experiences and ways in which the APCD shares Medicaid match dollars with its state Medicaid office. Once funding and its purpose are established, allocation can continue without burdensome reporting.

### *Data User/Requester Perspective*

Affordability is a key factor for many requestors. A data user will weigh the cost and quality of data as well as other factors when deciding which states to request data for studies and if the APCD value is equal to its cost. As noted above, states provide data pricing structure options that are quite varied. Some states provide cost of “per data file, per year” as well as “multi-year, multi-file” costs while others provide a wide range of structures. Depending on the user type and data access needs, costs may differ substantially.

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<sup>56</sup> Freedman Report on Medicaid Match Funding [https://freedmanhealthcare.com/wp-content/uploads/2017/11/Medicaid-Match-Webinar\\_FINAL.pdf](https://freedmanhealthcare.com/wp-content/uploads/2017/11/Medicaid-Match-Webinar_FINAL.pdf)

States often establish rules or options like scholarships for data requestors to pay less if there is a financial hardship or budget limitation, especially for student researchers. These discounts are either factored into the fee structure or data release is supported through budgeting like:

- Colorado, where the General Assembly appropriated \$500,000<sup>57</sup> to support eligible organizations requesting data.
- Arkansas<sup>58</sup> specifically discounts data for students with a larger discount for students in state (50%) than out of state (25%).
- The state of Maine is an example of a state that through statute provided the APCD with flexibility to waive or reduce fees when appropriate:
  - [Waiver Provisions](#)
    - The Maine Health Data Organization Board may reduce or waive the fees established in sections 3 and 4 in the event it determines that the entity requesting data has demonstrated either or both of the following:
      - Inability to pay. An inability to pay for data due to extenuating circumstances; or
      - Information/analysis publicly accessible. The requested data are to be used to improve the health of Maine residents and the resulting information, reports, and/or analytical products are to be in the public domain without charge and can be easily accessed within the time frame approved by the Maine Health Data Organization Board.

## Communication

Many of the previous sections noted the communication strategies states use on their websites, but it is important to highlight some strategies found on state APCD websites since they are critical from both state and requestor perspectives.

### *State Perspective*

The benefit of an effective APCD website can help attract well qualified data users. Sharing data with qualified users results in high caliber reports and analysis that can benefit the state. Additionally, quality research that makes headlines provides greater exposure for the data and its availability.

State APCDs that provide clear and organized information on data release policies and process can mitigate the administrative burden and reduce frustration from potential data users who'd rather not bother APCD with questions that could be answered online. And while the application process can be complicated, some states have lessened the burden on applicants by anticipating likely queries. Providing comprehensive details and using plain language, states may virtually eliminate the need to respond to questions like:

1. "How much does your data cost?"

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<sup>57</sup> <https://www.civhc.org/wp-content/uploads/2021/11/CIVHC-Financial-Assistance-Initiative.pdf>

<sup>58</sup> <https://www.arkansasapcd.net/Resources/APCDDataRequestPricing/>

2. “How do I get a copy of the data?”
3. “What is included in the data?”

Examples of states with easy-to-follow, detailed website pages for data release:

- Washington<sup>59</sup> state has a logically organized page with questions that a potential data requestor might ask; the page is likely designed from experience working with researchers in the past.
- Colorado’s<sup>60</sup> website, which is more nuanced, has a multi-page section offering custom reports and data release options with different requirements and costs associated.

Examples of states that are curating great work and featuring it on their APCD website:

- Delaware<sup>61</sup> shares a portal to public reports, has an “in the news” highlight on the main page, and easy-to-find details — including analytic portals — making information gleaned from the data accessible to all regardless of an individual’s proficiency with APCD.
- While the design on the Maine<sup>62</sup> website could use a makeover, the site is comprehensive and serves as a “one-stop shop” for legislative updates, data uses in the state, and details on data, including an interactive dashboard and process for data release.

Some states release press reports to highlight important and/or beneficial work conducted with APCD data. For example, a study completed using New Hampshire APCD data shined light on the impact of price transparency. NHID issued a press release to raise awareness and the study has since been referenced in articles by the Wall Street Journal, testimonies in Congress, and more. The NH APCD could benefit from the work done by other states and curate the work centrally rather than share useful information across multiple websites.

### *Data User/Requester Perspective*

States must consider the data from an outside user perspective and share key information so that the agency releasing the data minimizes the burden of inquiries and attracts qualified data users. At minimum, states provide interested data users with easily accessible data dictionaries.<sup>63</sup> A data dictionary is a summary of information about the data that typically includes the definitions, origin, usage, and format of the data. When states have different levels of release, there are associated variations of the dictionary to inform potential applicants of the fields available to them based on their application.

A potential data user will also benefit from knowing a bit more about the APCD data in a state before they begin the process of completing an application. Some states have documents available that detail issues identified

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<sup>59</sup> <https://www.wahealthcarecompare.com/wa-apcd-data-requests>

<sup>60</sup> <https://www.civhc.org/>

<sup>61</sup> <https://dhin.org/healthcare-claims-database/>

<sup>62</sup> <https://mhdo.maine.gov/>

<sup>63</sup> <https://mhdo.maine.gov/mhdo-data-dictionary/search>

with data fields — often called data release notes.<sup>64</sup> Some state APCDs will share notes at the same time that an approved user receives the data, while others have the notes publicly available. Data release notes might include details on poorly populated fields, proper use of field types, and information on the data that will be important for a user to be aware of for a variety of reasons. Examples might include:

- A data submitter made historical corrections since the last data were available
- Notes on specific issues with data submitters
- Versioning issues might be identified for one or more data submitters
- Some claims for a data submitter may not have complete eligibility records included

The timeliness of data collection and the availability of current data are often important factors when planning a research project, especially one that may include a multi-state analysis. A data user will want to know if data will be relevant and useful for study. If a researcher is doing a longer-term study, they may want to know how much time passes between extract updates.

1. Public information on years of available data, frequency of data collection or frequency of data release updates (annual, quarterly, or both)<sup>65</sup> Oregon has a detailed data user guide that also includes release notes.
2. Clear public information on what is included<sup>66</sup> in the data and how useful the data are for researchers, an example of an interactive dashboard detailing the data available in Colorado is pictured below:

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<sup>64</sup> <https://achiapcd.atlassian.net/wiki/spaces/ADRS/pages/2611380241/APCD+Release+Notes+Summary>

<sup>65</sup> <https://www.oregon.gov/oha/HPA/ANALYTICS/APAC%20Page%20Docs/APAC-Data-User-Guide.pdf>

<sup>66</sup> <https://www.civhc.org/get-data/whats-in-the-co-apcd/>

Image 7C. CO APCD Insights Dashboard

## CO APCD Insights Dashboard



## Appendix C: Preliminary Report

### ROAD MAP TO FINAL RECOMMENDATIONS

A preliminary report, *Recommendation Report for Expanded Use of the Minnesota All Payer Claims Database: initial Findings*,<sup>67</sup> was delivered to the Minnesota Legislature in February 2022 and is summarized in this appendix.

#### Report Summary

For the preliminary report, HSRI conducted an initial scan of data use practices across states and reviewed recent publications on APCDs.<sup>68</sup> The final report will more thoroughly consider the experiences by other states and the federal government concerning the dissemination of data and the data use practices. States with APCDs have a great deal to learn from one another and have often shared achievements, lessons learned, and opportunities for data use. As always, paramount in this work will be identifying ways to protect patient privacy and ensure data security.

More specifically, the following components, along with anticipated guidance from the U.S. Department of Health and Human Services (HHS), will make up the effort to develop final recommendations:

1. An in-depth environmental scan
2. Comprehensive engagement with Minnesota stakeholders
3. Identification of best practices

#### Environmental Scan

MDH will further evaluate existing data release policies and practices of other state APCDs, including those that have similar privacy requirements, as well as states whose data release practices have been noted as being exceptional. MDH will utilize the resources available through the National Association of Health Data Organizations (NAHDO) a national organization that coordinates efforts among states with APCDs and produce reference material that will be beneficial to the completion of the environmental scan. While few states produce the volume of research as Minnesota does, most do provide a process for data release to qualified entities and researchers to make use of the data in the benefit of their state's residents.

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<sup>67</sup> <https://www.health.state.mn.us/data/apcd/docs/apcdexpandaccesslegrpt.pdf>

<sup>68</sup> For example: Grace, K., Dworsky, M., Heins, S., Schwam, D., Shelton, S., Whaley, C., & Health Care, R. (2021). The History, Promise and Challenges of State All Payer Claims Databases Background Memo for the State All Payer Claims Database Advisory Committee to the Department of Labor. <https://aspe.hhs.gov/sites/default/files/private/pdf/265666/apcd-background-report.pdf>

Another key area that will be considered will be the within-state agency data sharing policies and practices in Minnesota that could inform the final recommendations.

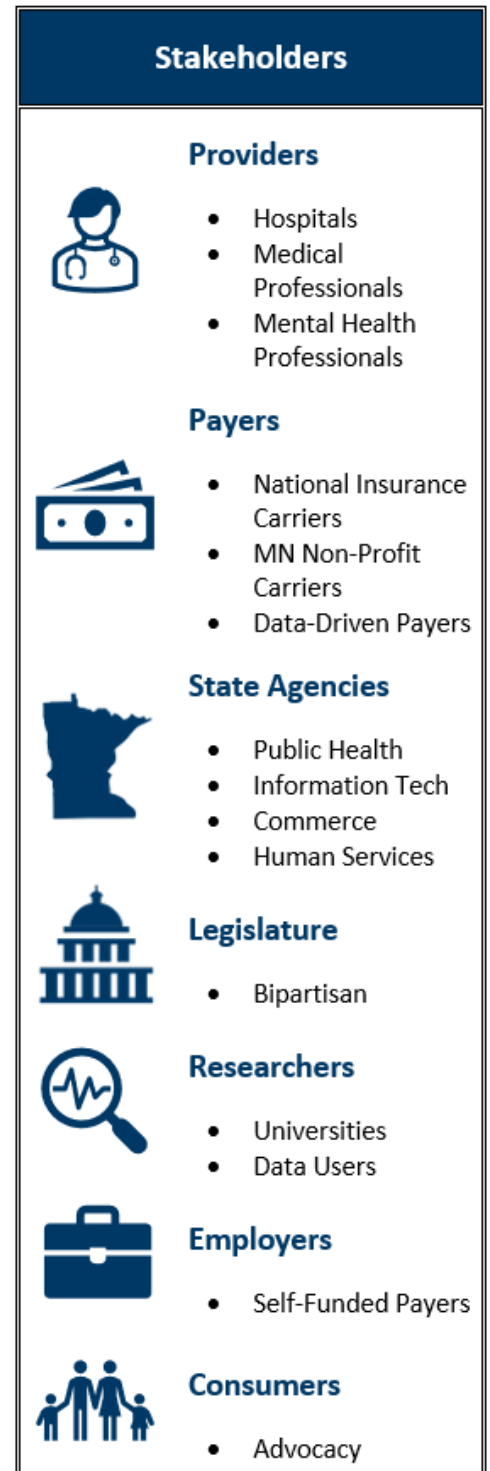
- **State Agency Partnerships** – Determine which state agencies will benefit most from MN APCD data and interest in using the data to advance their data-driven approach.
- **State-University Partnerships**<sup>69</sup> – Mutually beneficial university partnerships are popular with state APCDs because universities gain the ability to better contribute to the public benefit while states benefit from additional research.
  - Expedient cost-effective partnership
  - Expertise in data analytics and data science
  - Shared vision and trust
  - Understanding of state health policy and agency needs
  - Potential Federal Medicaid Match Funding

Additionally, MDH will evaluate federal agencies’ and national data organizations’ policies and practices for data release and determine if anything at the national level can inform and add value to the final recommendations.

## Stakeholder Engagement

Throughout the process of using the MN APCD, MDH has worked closely with a range of stakeholders. This has included working with providers and measurement experts on technical issues, and with groups of stakeholders

Figure 1B. Stakeholders



<sup>69</sup> Milbank Memorial Fund (n.d.) *Medicaid agency-state public university partnership: The value proposition for Medicaid agencies*. Retrieved December 22, 2021, from [https://www.milbank.org/wp-content/uploads/2020/09/Value\\_Prop\\_Medicaid-Agency\\_v5.pdf](https://www.milbank.org/wp-content/uploads/2020/09/Value_Prop_Medicaid-Agency_v5.pdf)



in 2014 and 2015 to consider effective use of the data.<sup>70</sup> Over time, MDH has also worked with employers, physicians, and public health experts on the development of research and to further increase the awareness of the data and emerging research findings. Most recently, MDH sought guidance from the community through a Request for Information (RFI) on new applications for the use of the MN APCD and from researchers on how to enhance the effectiveness of Minnesota's suite of PUFs. Stakeholder engagement is particularly critical for the development of recommendations related to how data governance can resolve the tensions associated with preferences by data users and philosophical approaches in the state to data use.

MDH plans to engage with stakeholders in Minnesota to discuss findings from the environmental scan, questions or concerns about data use, interest in use of the data, and best practices considerations for expanded data sharing. Stakeholders we plan to consult include but are not limited to the research community; Minnesota Departments of Human Services and Commerce; Minnesota State Employee Group Insurance Plan; MNSure; health insurers; health systems, including clinic and hospital staff; legislators and representatives of communities experiencing barriers in health equity.

In October of 2021, the Robert Wood Johnson Foundation published Recommendations from the National Commission to Transform Public Health Data Systems<sup>71</sup> that underscored that modern public health data systems, such as the MN APCD, is more than simply a collection of individual data points and is defined as the actors and sectors with data and agency to make decisions to advance the health and well-being of a community, population, and nation. Establishing an equitable and ethical data sharing framework that is governed to protect privacy will be important work that will be done with the stakeholders as the expanded use of the MN APCD is considered.

## Best Practices

The outcome of the work done in 2022 will determine what can be described as *best practices for Minnesota*, taking into consideration multiple views and perspectives. Data users' perspectives may describe best practices for data sharing differently than that of the state because of different priorities. Data users prefer a simplified application process with quick access to data, while state APCDs may view best practice as a measured process that favors careful consideration over a rapid timetable. Best practice for data release will be one that results in the Minnesota benefitting from the work of many quality data users and follows prudent practices for data protection.

Initial findings were also documented, presenting some best practices, these will be enhanced and adjusted throughout 2022 into Minnesota-specific best practices.

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<sup>70</sup> <https://www.health.state.mn.us/data/apcd/allworkgroups.html>

<sup>71</sup> National Commission to Transform Public Health Data Systems. (2021, October). Charting a course for an equity-centered data system. Robert Wood Johnson Foundation. <https://www.rwjf.org/en/library/research/2021/10/charting-a-course-for-an-equity-centered-data-system.html>

## Appendix D: Stakeholder Engagement

### OVERVIEW

Stakeholder engagement is critical for making practical recommendations in the best interest of Minnesotans to expand access and use of the MN APCD. MDH conducted 1:1 interviews and group listening sessions with nearly 70 diverse stakeholders representing government agencies, employers and payers, providers, researchers, and community and advocacy organizations. Stakeholder insights and perspectives were sought on the following topics:

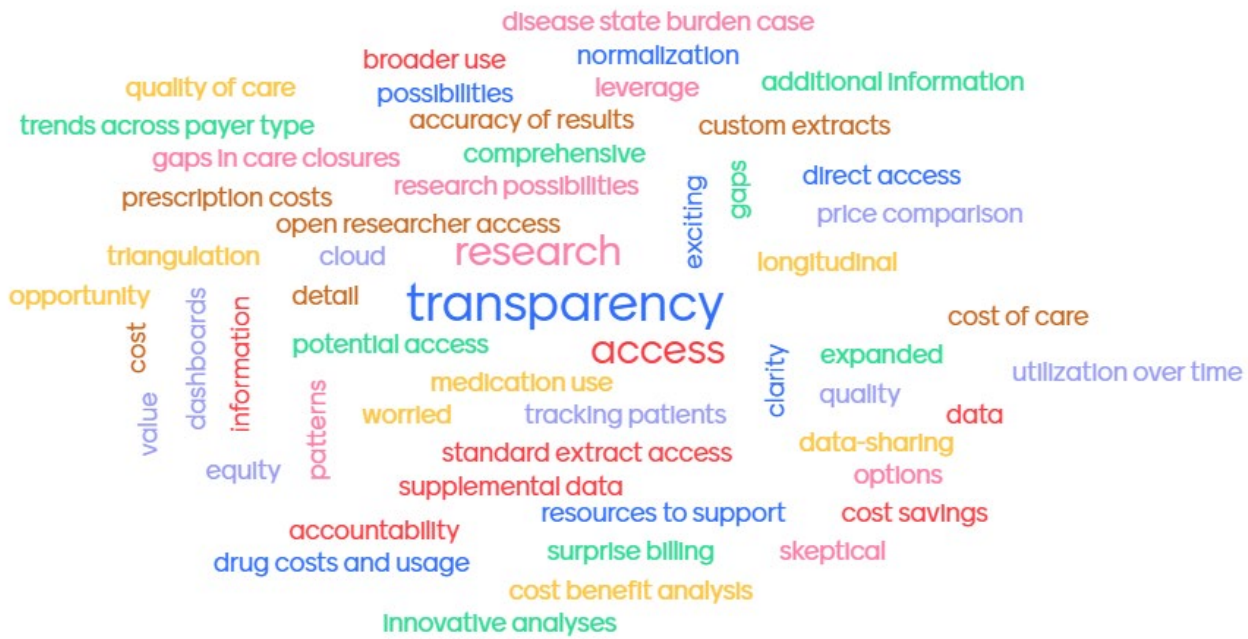
- Identify strengths, opportunities, and challenges within the current MN APCD.
- Outline what other states with APCDs are doing and gather feedback on the preliminary recommendations for more effective use of the MN APCD.
- Elicit feedback on data access and management, including options for accessing the data.
- Answer questions and listen to ideas and concerns related to expanded access and use of the MN APCD.

The recommendations integrated throughout this final report reflect the stakeholder feedback received, with key highlights including:

- The need to clearly document and clarify data governance policies and procedures, including roles and responsibilities.
- Support for developing and enforcing a Data Management Plan to guide the process from data submission to availability.
- Standardize and expand access to information, with security and protecting privacy at the forefront.
- Support for the development of a data sharing framework.
- Support for updates to the statutory language to enhance data collection, expand data access, and collection & release identifiable data with appropriate governance in place to protect privacy.
- Steep licensing or one-time use fees could be a barrier to accessing the data.
- Technical assistance and detailed documentation provided by MDH would be necessary.
- Access to Medicaid data within the MN APCD is important.
- Examples of how stakeholders would use the data if provided access.

After hearing how other states are using data from APCDs, stakeholders expressed excitement about the opportunities for the MN APCD via a word cloud, a visual representation of responses, with the most frequent responses in larger text:

Image 1D. Stakeholders' Word Cloud



## KEY TAKEAWAYS

### Opportunities

During the session, participants received an overview of the MN APCD, learned what other states are doing with APCD data, and heard opportunities for more effectively using the MN APCD before engaging in conversations about who could benefit from access to the MN APCD, preferences for accessing the data, data enhancements to consider, how the MN APCD could assist with work, ideas for data reporting, and potential drawbacks. The key takeaways from each group included:

Table 1D. Feedback Received from Stakeholder Groups

Topic	Group	Feedback
Preference for Data Access	Employers & Payers	<ul style="list-style-type: none"> <li>• Important to follow HIPAA minimum necessary standard and receive IRB approval and HITRUST certification</li> <li>• Publicize a detailed list of those with access to data and destruction receipts at the end of use</li> </ul>
	Community & Advocacy Organizations	<ul style="list-style-type: none"> <li>• Interested in low-cost direct access in a secure environment or custom reports</li> </ul>
	Government Agencies	<ul style="list-style-type: none"> <li>• Ease of use is important, along with streamlined access to the data using MDH cloud environment</li> </ul>
	Providers	<ul style="list-style-type: none"> <li>• Interested in direct access to the data within a secure environment</li> <li>• Data should not be allowed to be used for competitive advantage</li> </ul>

Topic	Group	Feedback
		<ul style="list-style-type: none"> <li>• Data access review committee is a necessary component</li> <li>• Would rather pay MDH for access to the data or analytic services, rather than other vendors</li> </ul>
	<b>Researchers</b>	<ul style="list-style-type: none"> <li>• Interested in direct access within a secure environment, standard extracts, and/or utilizing data sets within their own secure environments</li> <li>• Commercial data is insufficient for most researchers in the state and access to Medicaid data is important</li> </ul>
<b>Data Reporting</b>	<b>Employers &amp; Payers</b>	<ul style="list-style-type: none"> <li>• The ability to study the health system by geographic areas would allow plans to see where cancer screenings, among other services, are low and develop an outreach plan</li> <li>• MDH could report utilization per 1,000 for common healthcare procedures and services</li> <li>• Report on utilization by geography, race, ethnicity, and condition prevalence</li> <li>• Transparently report on cost information for providers, including physicians and hospitals, and health systems by payer</li> </ul>
	<b>Community &amp; Advocacy Organizations</b>	<ul style="list-style-type: none"> <li>• Produce dashboards on prescription drugs for advocates and consumers</li> <li>• Report on continuous eligibility</li> </ul>
	<b>Government Agencies</b>	<ul style="list-style-type: none"> <li>• Interested in dashboards developed by MDH, including spending trends by payer</li> <li>• Desire benchmarks for low value care and disease prevalence</li> </ul>
	<b>Providers</b>	<ul style="list-style-type: none"> <li>• Utilize geographic information to report on cost of services by payer and provider</li> <li>• Highlight out of pocket payments and costs for underinsured populations</li> </ul>
	<b>Researchers</b>	<ul style="list-style-type: none"> <li>• Identify barriers to access care by analyzing distance traveled for care</li> </ul>
<b>Data Enhancements</b>	<b>Employers &amp; Payers</b>	<ul style="list-style-type: none"> <li>• Prior to adding new data elements, need to ensure that the data are more accessible and usable, as it's an investment of staff resources to add elements and reformat existing data structures</li> <li>• Medicare data with member information would be helpful, from health plan and data aggregator perspectives</li> </ul>
	<b>Community &amp; Advocacy Organizations</b>	<ul style="list-style-type: none"> <li>• Collect race, ethnicity, and language</li> <li>• Desire data to allow for analysis on all protected classes of people</li> <li>• Some payers plan to use provisions in the No Surprises Act to only pay in network rates for certain procedures regardless of network status, and collection of network status would help inform this practice</li> </ul>

Recommendation Report for Expanded Use of the Minnesota All Payer Claims Database: Final Report

Topic	Group	Feedback
	<b>Government Agencies</b>	<ul style="list-style-type: none"> <li>Collect race, ethnicity, and language</li> <li>Collection of dental data would be of great value to state agencies to better understand oral health in communities</li> </ul>
	<b>Providers</b>	<ul style="list-style-type: none"> <li>The value of the data is dependent on access to more granular provider and member data elements, such as race and ethnicity</li> </ul>
	<b>Researchers</b>	<ul style="list-style-type: none"> <li>Collect race, ethnicity, language, and social determinants of health</li> <li>To better understand the price variation and access issues that Minnesotans face, it is important to collect and have access to details on providers</li> </ul>
<b>Potential Drawbacks</b>	<b>Employers &amp; Payers</b>	<ul style="list-style-type: none"> <li>Potential discrepancies and data lags between APCD and health plans</li> </ul>
	<b>Community &amp; Advocacy Organizations</b>	<ul style="list-style-type: none"> <li>Cost of data access</li> <li>Ability and capacity for staff to use the data</li> </ul>
	<b>Government Agencies</b>	<ul style="list-style-type: none"> <li>Data can be misunderstood if a user is unqualified</li> <li>Price transparency may have an unintended negative consequence on rural pharmacies and providers who rely on higher costs to survive</li> </ul>
	<b>Providers</b>	<ul style="list-style-type: none"> <li>Lack of ERISA self-funded payers is a concern, though data are still representative of population</li> <li>Value based payments are not currently included in data</li> </ul>
	<b>Researchers</b>	<ul style="list-style-type: none"> <li>Cost of data access – PhD students would need a lower cost option</li> <li>Time from request to data access needs to be short – excessive time could prevent data use</li> </ul>
	<b>Data Use Benefits</b>	<b>Employers &amp; Payers</b>
<b>Community &amp; Advocacy Organizations</b>		<ul style="list-style-type: none"> <li>Study health outcomes, health costs, and impacts of market consolidation on consumers</li> <li>Publication of prescription drugs that have large price increases or extremely high-cost drugs could benefit consumers and inform policy makers</li> <li>Use data to evaluate parity in payments of mental health providers and other healthcare providers</li> <li>Interested in studying mental health visits following a hospital stay: Can claims experience help determine fairness of policy for number of visits allowed?</li> </ul>

Topic	Group	Feedback
		<ul style="list-style-type: none"> <li>• Investigate if costs vary for an individual that has continuous coverage compared with someone has a gap in coverage and comes back into the system</li> <li>• Utilize MN APCD data better understand the impacts of consolidation and if it is causing a shift in leverage in the marketplace</li> </ul>
	<p><b>Government Agencies</b></p>	<ul style="list-style-type: none"> <li>• Benefit to the state to study disease in a community, whether rare or common, and adherence to treatment protocols</li> <li>• The data could be used for actuarial analysis to validate justifications for premium rate increases, especially if data included denied claims</li> <li>• Utilize MN APCD in place of some data calls issued to payers</li> <li>• Understand geographic disparities</li> <li>• Studying claims in rural areas can help agencies better understand the financial health of critical access providers</li> </ul>
	<p><b>Providers</b></p>	<ul style="list-style-type: none"> <li>• Using data at the county or zip code level could illuminate areas of the state with higher costs and/or lower access</li> <li>• Existing providers and payers could access details on local markets to allow for more meaningful and competitive contracting process</li> <li>• Access to data on the healthcare marketplace will provide new payers and providers with useful information to better understand the care needs of communities and typical payments made to providers across the state</li> <li>• Would be extremely valuable to understand more about the healthcare market by geographic areas and know the cost by population and trends by area for market innovation</li> </ul>
	<p><b>Researchers</b></p>	<ul style="list-style-type: none"> <li>• Data can be used to study quality and impact</li> <li>• Study movement of members across payers and providers</li> <li>• Studying claims data by zip code, especially if race and ethnicity were included, would provide the state with a greater understanding of access and use of the health system</li> <li>• Researchers talked of interest in studying health over time, through Medicaid, Commercial and Medicare to eliminate data gaps, such as many Minnesota seniors have a Medicare Advantage plan and would be included in the APCD but not Medicare data from the federal government</li> </ul>

## Familiarity with the MN APCD

As indicated during a voluntary poll during the stakeholder listening sessions, the level of familiarity with the MN APCD differed among stakeholders, with most unfamiliar or somewhat familiar with the dataset:

**Table 2D. Response Count and Percentages: Dataset Familiarity**

	Employers & Payers	Community & Advocacy Organizations	Government Agencies	Providers	Researchers	Total
<b>Familiar with the MN APCD</b>	<b>0%</b> (0/9)	<b>0%</b> (0/8)	<b>13%</b> (2/15)	<b>33%</b> (4/12)	<b>25%</b> (2/8)	<b>15%</b> (8/52)
<b>Somewhat familiar with the MN APCD</b>	<b>56%</b> (5/9)	<b>0%</b> (0/8)	<b>27%</b> (4/15)	<b>25%</b> (3/12)	<b>38%</b> (3/8)	<b>29%</b> (15/52)
<b>Unfamiliar with the MN APCD</b>	<b>22%</b> (2/9)	<b>63%</b> (5/8)	<b>53%</b> (8/15)	<b>33%</b> (4/12)	<b>25%</b> (2/8)	<b>40%</b> (21/52)
<b>Very unfamiliar with the MN APCD</b>	<b>11%</b> (1/9)	<b>0%</b> (0/8)	<b>7%</b> (1/15)	<b>8%</b> (1/12)	<b>0%</b> (0/8)	<b>6%</b> (3/52)
<b>Very familiar with the MN APCD</b>	<b>11%</b> (1/9)	<b>38%</b> (3/8)	<b>0%</b> (0/15)	<b>0%</b> (0/12)	<b>13%</b> (1/8)	<b>10%</b> (5/52)

## Considerations Most Important When Expanding Data Access and Use

As indicated during a voluntary poll during the stakeholder listening sessions, the most important aspect to consider when thinking about expanding data access and use is utility of the data extracts:

**Table 3D. Response Count and Percentages: Considerations for Expansion of Data Access and Use**

	Employers & Payers	Community & Advocacy Organizations	Government Agencies	Providers	Researchers	Total
<b>Utility of Data Extracts</b>	<b>50%</b> (5/10)	N/A	<b>38%</b> (3/8)	<b>43%</b> (3/7)	<b>38%</b> (3/8)	<b>42%</b> (14/33)
<b>Governance, including Data Release Committee</b>	<b>20%</b> (2/10)	N/A	<b>13%</b> (1/8)	<b>29%</b> (2/7)	<b>0%</b> (0/8)	<b>15%</b> (5/33)
<b>Privacy and Security</b>	<b>20%</b> (2/10)	N/A	<b>13%</b> (1/8)	<b>0%</b> (0/7)	<b>0%</b> (0/8)	<b>9%</b> (3/33)
<b>Formats for Accessing the Data</b>	<b>10%</b> (1/10)	N/A	<b>25%</b> (2/8)	<b>14%</b> (1/7)	<b>13%</b> (1/8)	<b>15%</b> (5/33)
<b>Documentation and Technical Assistance</b>	<b>0%</b> (0/10)	N/A	<b>0%</b> (0/10)	<b>0%</b> (0/7)	<b>25%</b> (2/8)	<b>6%</b> (2/33)
<b>Data Collection</b>	<b>0%</b> (0/10)	N/A	<b>0%</b> (0/8)	<b>0%</b> (0/7)	<b>0%</b> (0/8)	<b>0%</b> (0/33)
<b>Data Release Practices</b>	<b>0%</b> (0/10)	N/A	<b>13%</b> (1/8)	<b>14%</b> (1/7)	<b>25%</b> (2/8)	<b>12%</b> (4/33)

\*NA – Given the unfamiliarity with the MN APCD from Community & Advocacy Organizations, the poll was not conducted.

## Listening Sessions

### *Employers and Payers*

Of the 22 employer and insurance company representatives invited to participate in the session, 11 attended on *Monday, Oct. 24, 2022, from 12:30-2 p.m.*

Representatives from the following organizations were in attendance:

- 3M
- Cirdan Health Systems
- HealthPartners
- Medica
- Pharmaceutical Care Management Association
- PrimeWest Health
- United Healthcare

After hearing how other states are using APCD data, employers and payers shared what excites them about the opportunities for the MN APCD:

**Image 2D. Word Cloud: Employers and Payers**



### *Community and Advocacy Organizations*

Of the 22 community and advocacy organization representatives invited to participate in the session, 9 attended on *Friday, Nov. 4, 2022, from 9-10:30 a.m.*

Representatives from the following organizations were in attendance:

- Metropolitan Center for Independent Living



- MN Association of Community Health Centers (MNACHC)
- National Alliance on Mental Illness (NAMI)
- O’Connell Consulting
- Sherburne County Health and Human Services
- The Leukemia & Lymphoma Society
- Wilder Research

After hearing how other states are using APCD data, community and advocacy organization representatives shared what excites them about the opportunities for the MN APCD:

**Image 3D. Word Cloud: Community and Advocacy Organizations**

**Image 3: Employers’ and Payers’ Word Cloud**



### *Government Agencies*

Of the 28 government agency representatives invited to participate in the session, 16 attended on *Monday, Oct. 24, 2022, from 10-11:30 a.m.*

Representatives from the following Minnesota state agencies were in attendance:

- Department of Administration
- Department of Commerce
- Department of Health
- Division of Health Policy
- Department of Human Services
- Management and Budget: State Employee Group Insurance Program
- MMCAP Infuse, a division of the Office of State Procurement
- MN Rare Disease Advisory Council
- MN Sure

After hearing how other states are using APCD data, government agency representatives shared what excites them about the opportunities for the MN APCD:

**Image 4D. Word Cloud: Government Agencies**



### *Providers*

Of the 22 provider representatives invited to participate in the session, 15 attended on *Wednesday, Oct. 26, 2022, from 8:30-10 a.m.*

Representatives from the following provider organizations were in attendance:

- Allina Health
- AveraHealth
- Community Pharmacy Enhanced Services Network (CPESN)
- Fairview
- Hennepin Healthcare Research Institute
- Minnesota Academy of Family Physicians (MAFP)
- Minnesota Hospital Association
- Minnesota Medical Association
- Nice Healthcare
- Sanford Health

After hearing how other states are using APCD data, providers shared what excites them about the opportunities for the MN APCD:

*Image 5D. Word Cloud: Providers*



### *Researchers*

Of the 14 research organization representatives invited to participate in the session, 10 attended on *Monday, Oct. 31, 2022, from 12-1:30 p.m.*

Representatives from the following provider organizations were in attendance:

- Carlson School of Business
- Mayo
- Stratis Health
- University of Minnesota
- University of Minnesota – School of Pharmacy

After hearing how other states are using APCD data, researchers shared what excites them about the opportunities for the MN APCD:

*Image 6D. Word Cloud: Researchers*



Furthermore, researchers' use of the data could benefit the state through:

*Image 7D. Word Cloud: Benefits of Researchers' Data Use*



## Appendix E: Example Application



This application (“Data Application”) is the first step in all requests for access to the MN APCD data products, in accordance with {insert statute and/or rule}

### Instructions

Please complete this Data Application and return to the MN APCD {insert email@state.mn.gov}. **Final decisions will not be made until a completed Data Application is accepted, including all attachments and signed agreements.** An incomplete application will not be considered and returned to the applicant.

The MN APCD will follow up within 5 business days to provide an application processing time estimate. Routine requests typically take 30 days to process.

Project Summary Information	
Project Title	
Date of Application	
Organization Requesting Data	
Principal Researcher	
Contact Person	
Title	
Email	
Phone Number	
Address	

Project Schedule	
Proposed Project Start Date:	
Proposed End Date:	
Proposed Publication or Release Date	

### Professional Qualifications

1. Description of Principal Researcher/Investigator including:
  - a. description of previous research and/or publications, including experience with claims data
  - b. university affiliations, private research organizations, medical center, state agency or other institution

- c. attach resume or CV if it includes the above
- 2. List any or all other researchers wishing to access data for this project
  - a. Include name(s) and qualifications
  - b. Attach resume(s) if includes qualifications

### Project Summary and Research Protocols

1. Summary of background, purposes, and origin of the research:
2. Statement of the health-related problem or issue to be addressed by the research:
3. Research design and methodology, including either the topics of exploratory research or the specific research hypotheses to be tested:
4. How will this research benefit Minnesota or the residents of Minnesota?
5. Have you obtained approval from the Institutional Review Board (IRB) for this project?
  - No or N/A, reason:
  - In progress. Anticipated approval date:
  - Yes. If so please attach a copy of the approval.
6. Data Request level
  - Single Project/Short term
  - Single Project/ Long term Will require refreshed data
  - State Agency Single Project license Will require refreshed data
  - State Agency Multi Project license Will require refreshed data
7. Type of Data Requested
  - Standard Research Data set
  - Custom Limited Data set
  - {Other data access options determined by MN}
  - Enhanced tables designed by MDH
8. Data Type – *What types of data files do you need for your project purpose?*
  - Medical Claims (**MC**) – Includes inpatient, outpatient, and professional claims in a variety of settings
  - Member Eligibility (**ME**) – Includes details on members eligible for insurance coverage included in the data with all Personal Identifiable Information (PII) removed.
  - Pharmacy Claim (**PC**) – Related to claims for prescriptions
9. Lines of Business Requested
  - Commercial Payers
  - Medicaid - requires review and approval by the MN office of Medicaid to make sure alignment with administration of the Medicaid program as required by federal law.
  - Medicare Fee For Service {confirm MN DUA with HHS allows and for what purpose}
10. Years of Data Requested – what year of claims do you need to complete your research?

- 2015
- 2016
- 2017
- 2018
- 2019
- 2020
- 2021
- 2022

11. Distribution of the Report or Product – *Requires review before publication*

If you are producing a report for publication in any medium (print, electronic, lecture, slides, etc.) the MN APCD Administrator must review the report prior to public release. This requirement is further spelled out in the Data Use Agreement. The MN APCD Administrator will review the report for compliance with CMS cell suppression rules, risk of inferential identification, and consistency with the purpose and methodology described in this Application. Do you acknowledge this requirement?

- Yes
- No

12. Linkages to Other Data Sets – The MN APCD cannot be used to attempt to re-identify individuals included in the data, especially when used with another data source. Will you attempt to link the data?

- Yes
- No

a. If Yes, please provide detail on the proposed use of data linkage:

- Which data elements will be used to perform linkage?
- What data source will be used with the MN APCD data?
- If attempted linkage is successful, what new data elements will appear in the work as a result?
- Why is data linkage necessary for this project?
- Has the proposed linkage been approved as a part of an IRB or other review board?
  - Yes, please provide copy
  - In progress, anticipated approval date \_\_\_\_\_
  - If no, please provide a reason

13. Data Management Plan

- a. Attach a copy of your organization's data privacy and security policies and procedures.
- b. Have you or any member of the project team been involved in a project that experience a data security incident? If so, please describe the incident, the response, and subsequent policy or procedure changes that occurred.
- c. Describe safeguards in place to protect the data during the duration of the project. Please include
  - i. Personnel/staffing safeguards including training, confidentiality agreements, and procedures to ensure only those approved have access to the data
  - ii. Technical and physical safeguards including physical security protocols of office and technical security in place to prevent unintended access to the data
  - iii. Will data be stored on a server? If so, describe how your organization prevents copying and transferring of data to local workstations and maintains the required encryption of the data in motion and at rest.



## Appendix F: Permitted Uses That Allow for Data Sharing Under HIPAA

The HIPAA Privacy Rule specifies the allowance for data sharing for the purposes of public interest and benefits, as well as for research purposes. Below is an excerpt from the HIPAA privacy rule regarding permitted uses and disclosures.

**Permitted Uses and Disclosures.** A covered entity is permitted, but not required, to use and disclose protected health information, without an individual’s authorization, for the following purposes or situations: (1) To the Individual (unless required for access or accounting of disclosures); (2) Treatment, Payment, and Health Care Operations; (3) Opportunity to Agree or Object; (4) Incident to an otherwise permitted use and disclosure; **(5) Public Interest and Benefit Activities; and (6) Limited Data Set for the purposes of research, public health or health care operations.**<sup>72</sup> Covered entities may rely on professional ethics and best judgments in deciding which of these permissive uses and disclosures to make.

**Public Interest and Benefit Activities.** The Privacy Rule permits the use and disclosure of protected health information, without an individual’s authorization or permission, for 12 National Priority Purposes.<sup>73</sup> These disclosures are permitted, although not required, by the Rule in recognition of the important uses made of health information outside of the health care context. Specific conditions or limitations apply to each public interest purpose, striking the balance between the individual privacy interest and the public interest need for this information.

**Twelve National Priority Purposes Allowing Disclosure of Health Information.** *Required by Law, Public Health Activities, Victims of Abuse, Neglect or Domestic Violence, Health Oversight Activities, Judicial and Administrative Proceedings, Law Enforcement Purposes, Decedents, Cadaveric Organ, Eye, or Tissue Donation, **Research**, Serious Threat to Health or Safety, Essential Government Functions, and Workers’ Compensation.*

**Research.** “Research” is any systematic investigation designed to develop or contribute to generalizable knowledge.<sup>74</sup> The Privacy Rule permits a covered entity to use and disclose protected health information for research purposes, without an individual’s authorization, provided the covered entity obtains either: (1) documentation that an alteration or waiver of individuals’ authorization for the use or disclosure of protected health information about them for research purposes has been approved by an Institutional Review Board or Privacy Board; (2) representations from the researcher that the use or disclosure of the protected health information is solely to prepare a research protocol or for similar purpose preparatory to research, that the researcher will not remove any protected health information from the covered entity, and that protected health information for which access is sought is necessary for the research; or (3) representations from the researcher that the use or disclosure sought is solely for research on the protected health information of decedents, that

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<sup>72</sup> 45 C.F.R. § 164.502(a)(1).

<sup>73</sup> See 45 C.F.R. § 164.512.

<sup>74</sup> The Privacy Rule defines research as, “a systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge.” 45 C.F.R. § 164.501.

the protected health information sought is necessary for the research, and, at the request of the covered entity, documentation of the death of the individuals about whom information is sought.<sup>75</sup> A covered entity also may use or disclose, without an individuals' authorization, a limited data set of protected health information for research purposes<sup>76</sup> See additional guidance on research<sup>77</sup> and NIH's publication of "Protecting Personal Health Information in Research: Understanding the HIPAA Privacy Rule."<sup>78</sup>

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<sup>75</sup> 45 C.F.R. § 164.512(i).

<sup>76</sup> 45 CFR § 164.514(e).

<sup>77</sup> <https://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/research.html>

<sup>78</sup> [http://privacyruleandresearch.nih.gov/pdf/HIPAA\\_Privacy\\_Rule\\_Booklet.pdf](http://privacyruleandresearch.nih.gov/pdf/HIPAA_Privacy_Rule_Booklet.pdf)

## Appendix G: Data Sharing Security Provisions

The HIPAA Privacy Rule details data sharing security provisions. This appendix highlights those provisions.

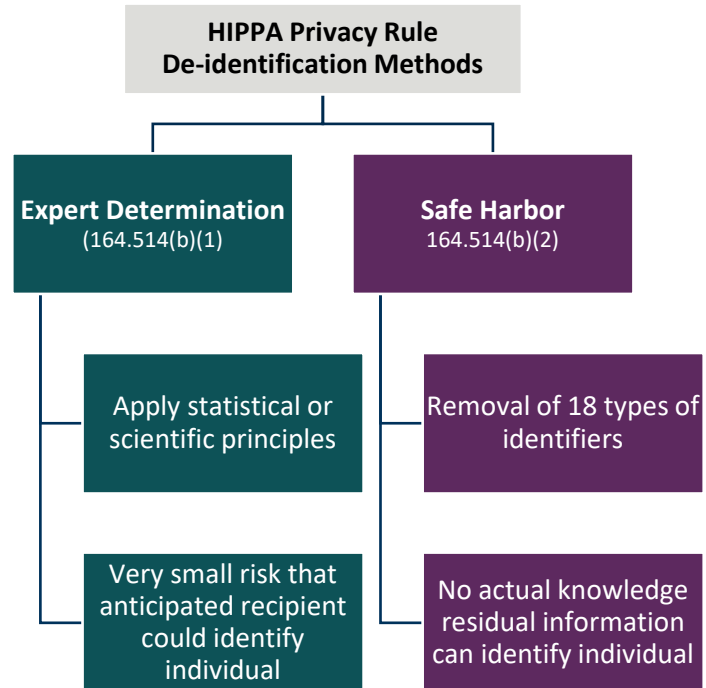
**Protected Health Information.** The Privacy Rule protects all “individually identifiable health information” held or transmitted by a covered entity or its business associate, in any form or media, whether electronic, paper or oral. The Privacy Rule calls this information “protected health information (PHI).”<sup>79</sup>

**Figure 1G. HIPPA Privacy Rule De-identification Methods** “Individually identifiable health information” is information, including demographic data, that relates to: the individual’s past, present or future physical or mental health or condition, the provision of health care to the individual, or the past, present, or future payment for the provision of health care to the individual, and that identifies the individual or for which there is a reasonable basis to believe it can be used to identify the individual.<sup>13</sup> Individually identifiable health information includes many common identifiers (e.g., name, address, birth date, social security number).

**De-Identified Health Information.** There are no restrictions on the use or disclosure of de-identified health information. De-identified health information neither identifies nor provides a reasonable basis to identify an individual.<sup>80</sup> There are two ways to de-identify information; either: (1) a formal determination by a qualified statistician; or (2) the removal of specified identifiers of the individual and of the individual’s relatives, household members, and employers is required and is adequate only if the covered entity has no actual knowledge that the remaining information could be used to identify the individual.<sup>81</sup>

45 C.F.R. § 164.514(e). A limited data set is protected health information that excludes the following direct identifiers of the individual or of relatives, employers, or household members of the individual:

- Names
- Postal address information, other than town or city, state and zip code



<sup>79</sup> 45 C.F.R. § 160.103

<sup>80</sup> 45 C.F.R. §§ 164.502(d)(2), 164.514(a) and (b).

<sup>81</sup> 45 C.F.R. § 164.514(b)

- Telephone numbers
- Fax numbers
- Electronic mail addresses
- Social security numbers
- Medical record numbers
- Health plan beneficiary numbers
- Account numbers
- Certificate/license numbers
- Vehicle identifiers and serial numbers, including license plate numbers
- Device identifiers and serial numbers
- Web Universal Resource Locators (URLs)
- Internet Protocol (IP) address numbers
- Biometric identifiers, including finger and voice prints
- Full face photographic images and any comparable images

45 C.F.R. § 164.514(e)(2)

A limited data set is designed to meet the requirements of the Safe Harbor Method. A limited data set is protected health information from which certain specified direct identifiers of individuals and their relatives, household members, and employers have been removed. A limited data set may be used and disclosed for research, health care operations, and public health purposes, provided the recipient enters into a data use agreement promising specified safeguards for the protected health information within the limited data set. The health information that may remain in the information disclosed includes:

- Dates such as admission, discharge, service, birth date, date of death
- City, state, five-digit or more zip code
- Ages in years, months or days, or hours

It is important to note that this information is still protected health information, or “PHI,” under HIPAA. It is not de-identified information and is still subject to the requirements of the Privacy Regulations.

**Limiting Uses and Disclosures to the Minimum Necessary.** A central aspect of the Privacy Rule is the principle of “minimum necessary” use and disclosure. A covered entity must make reasonable efforts to use, disclose, and request only the minimum amount of protected health information needed to accomplish the intended purpose of the use, disclosure, or request.<sup>82</sup> A covered entity must develop and implement policies and procedures to reasonably limit uses and disclosures to the minimum necessary. When the minimum necessary standard applies to a use or disclosure, a covered entity may not use, disclose, or request the entire medical record for a particular purpose, unless it can specifically justify the whole record as the amount reasonably needed for the purpose.

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<sup>82</sup> 45 C.F.R. §§ 164.502(b) and 164.514 (d).

## Appendix H: Example DUA



### MN APCD Data Use Agreement

#### DATA USE AGREEMENT

**THIS DATA USE AGREEMENT** (“**Agreement**”) is made and entered into as of [DATE] (“**Effective Date**”) by and between the Minnesota MDH of Health (“**MDH**”) and [Organization] (“**Data User**”) with office located [address], (individually a “**Party**”; collectively the “**Parties**”).

The health care claims data sets are received by MDH from health insurance carriers per Minnesota Revised Statutes [section 62U.04](#) and Minnesota Rules, [chapter 4653](#) and appendices. Access to the health care claims data for the MN APCD project can be provided pursuant to Minnesota statute {to be determined} and Minnesota Rules {to be determined} and the Data Recipient is requesting to receive access to the Data Sets for research purposes from MDH.

MDH and Data User agree as follows:

#### 1. DEFINITIONS

- 1.1. “**Agreement**” shall mean this Limited Use Data Agreement, and the Application for Access (“**Application**”) to the Data Sets which is attached and incorporated herein by this reference.
- 1.2. “**Data Recipient**” is defined as the individual researcher, the organization or entity employing the researcher, and the Principal Investigator.
- 1.3. “**Limited Use Data Set**” or “**Data Sets**” are defined as a health care claims data set that contains restricted data elements in which all direct patient identifiers have been encrypted, any information which could lead to indirect or direct identification of abortion providers has been removed, and all insured group or policy numbers have been encrypted.
- 1.4. “**Law**” is defined as all applicable federal, state, regulations and rules including but not limited to the Federal Privacy Act; Health Insurance Portability and Accountability Act (“**HIPAA**”) 42 U.S.C. §1320.
- 1.5. “**Minnesota MDH of Health**” (“**MDH**”) is the designated entity that collects health claims data.
- 1.6. “**Direct patient identifiers**” is defined as any data or information accessible by Data Recipient that can be used to identify or locate a natural person, including but not limited to: name, address, telephone number, email address, or social security number. Direct Patient Identifiers includes identifiers, demographic or behavioral data when such data either alone or in combination with other data is linked or has the capacity to be linked to a specific person. Direct Patient Identifiers also includes “health information” and “personally identifiable health information” as defined by HIPAA.

- 1.7. **“Principal Researcher”** is the person responsible for the Data User’s research project identified in the Application and is responsible for the establishment and maintenance of security protocols to prevent authorized use or disclosure of Data Sets.
- 1.8. **“Security Breach”** is defined as any actual or reasonably suspected breach of safeguards to protect Data Sets.

## 2. TERM OF AGREEMENT AND TERMINATION

- 2.1. This Agreement shall commence on the Effective Date set forth above and shall continue until [Date] (**“Expiration Date”**), unless sooner terminated. MDH, at its sole discretion, may terminate this Agreement in whole or part at any time without notice.
- 2.2. Effect of Termination. Upon termination or expiration of this Agreement for any reason, Data Recipient shall within thirty (30) days return all Data Sets and shall provide written certification of the return and/or destruction of all Data Sets and copies of Data Sets.
- 2.3. Renewals. If Data Recipient determines that its research project needs to be extended, Data Recipient shall submit a written request to MDH at least sixty (60) days before the Expiration Date.

## 3. DATA SECURITY PROCEDURES AND PRIVACY

- 3.1. Limitation on use. Data Recipient shall:
  - 3.1.1. Only use the Data Sets for the purpose specified in the Application, and shall not use, disclose or sell Data Sets or any information derived from Data Sets to any third parties without the written consent of MDH.
  - 3.1.2. Not use, disclose, transfer, or sell Data Sets or statistical tabulations derived from Data Sets to any individual or organization other than as described in the Application and only to the extent permitted by Law and this Agreement.
  - 3.1.3. Not attempt to ascertain the Personal Information of individuals, employer groups, or purchaser groups in the Data Sets, and if known or discovered Data Recipient shall not disclose, use, transfer or sell the Personal Information.
  - 3.1.4. Not attempt to ascertain any information removed from or encrypted in the Data Sets, and if known or discovered Data Recipient shall not disclose, use, transfer or sell the information.
  - 3.1.5. Not publish or make available outside of Data Recipient’s organization any detailed or summary data that could be used to constructively identify personal information.
  - 3.1.6. Not publish or make available outside of Data Recipient’s organization any Personal Information that could be used to identify providers of abortion services.
  - 3.1.7. Provide MDH with a preview copy of proposed reports or publications based in whole or part on the Data Sets at least fifteen (15) days prior to the publication or release, and MDH shall review the report or publication for adherence to the terms of the Agreement and Application.
  - 3.1.8. Not release any report or publication based in whole or in part from Data Sets when MDH determines such report or publication breaches the terms of this Agreement.
  - 3.1.9. Acknowledge MN APCD as the source of the data used in any report, publication, or presentation created by the Data Recipient based in whole or part on the Data Sets.
  - 3.1.10. Specify in writing in all reports, publications, and presentations that all analyses, conclusions, and recommendations derived from the Data Sets are solely the Data Recipients.

3.2. Safeguards.

- 3.2.1. Data Recipient shall implement and maintain appropriate measures to ensure the security and confidentiality of Data Sets; to protect against any threats or hazards to the security or integrity of Data Sets; protect against the unauthorized access, use, or publication of Data Sets. Data Recipient shall maintain physical, electronic, and procedural controls and safeguards in compliance with Law, to prevent the unwarranted disclosure of Data Sets or Personal Information.
- 3.2.2. Procedures to safeguard Data Sets include at a minimum the following:
  - 3.2.2.1. Adequate physical security of all premises where Data Sets are stored or processed.
  - 3.2.2.2. Reasonable precautions were taken with respect to the employment of and access given to personnel engaged who could have access to Data Sets.
  - 3.2.2.3. Appropriate authentication credentials are implemented.
  - 3.2.2.4. Appropriate password complexity standards are implemented to protect Data Sets from wrongful access; and
  - 3.2.2.5. Testing and auditing of controls.
- 3.2.3. Notification of unauthorized access or loss of Data Sets. Data Recipient shall notify MDH within twenty-four (24) hours of any actual or reasonably suspected breach of security or breach of access, use contrary to this Agreement or Application, or loss or destruction to Data Sets. Data Recipient shall comply with applicable regulatory obligations and cooperate with MDH on investigating the security breach.

**4. CELL SUPPRESSION POLICY**

- 4.1. The Recipient agrees that any use of MN-APCD Data in the creation of any Data output (manuscript, table, chart, study, report, etc.) that is shared with anyone who is not an Authorized Data
- 4.2. Users shall adhere to the following minimum thresholds.
  - 4.2.1. No cell size less than 11 may be displayed (such as but not limited to admittances, discharges, patients, and services). Also, no use of percentages or other mathematical formulas may be used if they result in the disclosure of a cell less than 11.
  - 4.2.2. Data output and analytics must use complementary cell suppression techniques to ensure that cells with fewer than 11 observations cannot be used to identify an individual person by manipulating Data output (e.g., in adjacent rows, columns or other manipulations).
  - 4.2.3. Information that could be used alone or in combination with other information to identify an individual shall not be published in any form.
  - 4.2.4. The Recipient will not attempt to identify individuals in the APCD data or to link records included in the APCD data to any other individually identifiable source of information without the express written approval by MDH.

## **5. WARRANTIES AND COVENANTS OF DATA RECIPIENT**

- 5.1. Data Recipient represents, warrants, and covenants the following:
  - 5.1.1. All Data Sets shall be used only to the extent and as indicated in the Application, and this Agreement.
  - 5.1.2. All Data Sets shall be returned to MDH within thirty (30) days of the Expiration Date.
  - 5.1.3. Data Recipient has no other agreement, relationship, or commitment to any person or entity that conflicts with its obligations under this Agreement.
  - 5.1.4. That it has the right, power, and authority to execute this Agreement.

## **6. GENERAL PROVISIONS**

- 6.1. The obligations and limitations of this Agreement shall extend beyond the termination or expiration of this Agreement.
- 6.2. Data Recipient acknowledges and agrees to indemnify and hold harmless MDH against any costs, liabilities, suits, or damages as a result of the Data Recipient's use or disclosure in whole or part of Data Sets.
- 6.3. In the event that any provision of this Agreement shall be held invalid, illegal, or otherwise unenforceable for any reason, the validity, legality, and enforceability of the remaining provisions shall not be affected or impaired.
- 6.4. Data Recipient acknowledges and agrees that failure to adhere to the terms of this Agreement shall result in the immediate recall by MDH of all Data Sets provided hereunder, and Data Recipient shall not use, disclose, or publish any report, publication, or presentation derived from Data Sets.
- 6.5. Neither Party may assign or transfer this Agreement or any of its rights, duties, or obligations under this Agreement, and any such attempt shall be deemed null and void.

## **7. RESULTS AND REPORTS.**

- 7.1. The Receiving Organization agrees to provide the APCD Administrator with a copy of any results derived from the APCD Data and information regarding the outcome of the project, as it is described in the Application.
- 7.2. The Receiving Organization must obtain approval from the APCD Administrator to release any reports or outputs prior to distribution outside the named project team. Distribution includes but is not limited to: peer review, submission to any federal or state agency, presentation of findings, or synopsis of research.
- 7.3. The APCD Administrator will review the report within six weeks of receipt to confirm:
  - 7.3.1. The Receiving Organization's compliance with minimum cell size and complementary cell suppression rules;
  - 7.3.2. That the report or output has incorporated appropriate protections to prevent inferential identification; and
  - 7.3.3. That the report or output is consistent with the project description contained in the Receiving Organization's Application, as approved.



**8. ADDITIONAL PROJECTS.**

- 8.1. Use of the same Data for a project other than the one described in this Agreement must be approved through a separate application process.
- 8.2. The Receiving Organization understands and agrees that original or derivative Data file(s) cannot be reused or further disclosed without prior written approval from the APCD Administrator.

**9. ANTITRUST COMPLIANCE AND INDEMNIFICATION.**

- 9.1. Receiving Organization agrees to treat APCD Data confidentially, as specified in this Agreement, and not to use, or enable any other parties to use, the APCD Data for anti-competitive or other unlawful purposes, including but not limited to price-fixing, market or customer allocation, service or output restriction, price stabilization, or any other agreement or coordination among parties that in any way restricts or limits competition.
- 9.2. Receiving Organization agrees to indemnify and hold CIVHC harmless for any antitrust liability, damages, judgments, fees, expenses, awards, penalties (including civil monetary penalties), and costs (including reasonable attorney's and court fees and expenses) arising from or relating in any way to the APCD Data, or that in any way involve use of the APCD Data.
  - 9.2.1. Such indemnification shall include, but not be limited to, payment by Receiving Organization of any fines, penalties, or damages of any sort, including but not limited to compensatory, treble, punitive, or any other damages, fines, or penalties assessed against MDH for any antitrust violation arising from or relating in any way or any part to the APCD Data or use of the APCD Data, as well any and all of MDH's related legal fees, costs, and/or other expenses incurred in or arising from the matter.
- 9.3. Receiving Organization further agrees that it shall not attempt to identify, "reverse engineer," decompile, or in any other way attempt to discern the identities of specific parties that have been de-identified in the APCD Reports, nor shall Receiving Organization try to translate, convert, adopt, alter, modify, enhance, add to, delete, or tamper with any APCD Data or in any other way attempt to calculate or determine specific parties' prices from the APCD Data.

By signing this Agreement, the Receiving Organization agrees to abide by all provisions set out in this Agreement.

**SIGNATURES:**

**For the MN APCD:**

**For Receiving Organization:**

**Signature:**  
**Name:**  
**Title:**  
**Date:**

**Signature:**  
**Name:**  
**Title:**  
**Date:**

## Appendix I: Abbreviations

APCD – All Payer Claims Database

APM – Alternative Payment Models

APCD-CDL – Common Data Layout (APCD-CDL™)

CFR – Code of Federal Regulations

CMS – Centers for Medicare and Medicaid Services

DOL – Department of Labor

DUA – Data Use Agreement

ERISA – Employee Retirement Income Securities Act of 1974

FFS – Fee for Service

HIPPA – Health Insurance Portability and Accountability Act

HHS – United States Department of Health and Human Services

HSRI – Human Services Research Institute

IAA – Interagency Agreement

IRB – Institutional Review Board

MCO – Medicaid Managed Care

MDH – Minnesota Department of Health

MME – Morphine Milligram Equivalents

MOU – Memorandum of Understanding

MNIT – Minnesota Information Technology Services

NAHDO – National Association of Health Data Organizations

NCBP – Non-Claims Based Payments

PUF – Public Use File

REL – Race, Ethnicity, Primary Language

SAPCDAC – State All-Payer Claims Databases Advisory Committee

TPA – Third Party Administrator



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