



Recommendations to the Georgia APCD Advisory Committee Processes for Access and Release of APCD Data

*Approved by the APCD Data Privacy, Security, and Access Workgroup and
the APCD Use Case Workgroup on April 28, 2022*

Introduction

The All-Payer Claims Database (APCD) Data Privacy, Security, and Access (DPSA) Workgroup and the APCD Use Case Workgroup, two expert panels convened by the Office of Health Strategy and Coordination (OHSC) to support the work of the APCD Advisory Committee, met jointly on April 28, 2022, to review a set of draft recommendations for processes to ensure appropriate use and release of APCD data. The draft recommendations had been synthesized from discussions at previous workgroup meetings on the topics enumerated in the list below:

1. Considerations for permitting access for external users and entities to APCD data
2. Processes to ensure requests for the use of APCD data are appropriately reviewed
3. Processes to ensure APCD data is managed appropriately upon release for an approved purpose
4. Considerations for providing ongoing stakeholder support to the Advisory Committee
5. Considerations for ensuring reports are meaningful and made regularly to the Advisory Committee

The draft recommendations were approved unanimously by attending members of both workgroups during the joint meeting. Minor edits have been made in this document to reflect the thoughtful discussion by workgroup members about each of the final recommendations on data access and release.

Additional recommendations from the Use Case Workgroup, the DPSA Workgroup, and other groups as needed, will be presented to the APCD Advisory Committee in separate documents.

Recommendations Related to Data Access and Release

Recommendation #1: Apply appropriate oversight mechanisms.
Establish an eight-member Data Review Committee (DRC) to serve in an advisory role to the APCD Administrator.

The data collected in an APCD will provide value for multiple types of research, policy analysis, and other purposes. As external parties request APCD data, it will be imperative to assure the data is safeguarded and used appropriately. The Workgroups recommend a **Data Review Committee (DRC) be established** in line with best practices adopted by other states, to:

1. determine whether requests for data are consistent with the overall statutory intent of the APCD, and
2. review whether a requestor has sufficient processes in place to protect the data being requested (access, storage, use, destruction, etc.).

The Workgroups recommend that the APCD Administrator chair the DRC and suggests the committee be comprised of *a health insurer representative, a health care facility representative, a physician, a researcher, a chief privacy and security officer, an employee of the state's Medicaid agency (The Department of Community Health (DCH)), an employee of The Department of Public Health (DPH), and a consumer or employer.* Additionally, OHSC recommends that an OHSC representative be added to the committee. It should be noted that the Workgroups considered including a nurse and a pharmacist to expand sector representation on the DRC but opted to make the recommendation as outlined here out of concern that a larger DRC could have negative impacts on its ability to work efficiently and effectively. As an alternative, the DRC could adopt a process for engaging subject matter experts as needed to represent these and other additional constituencies.

Recommendation #2a: Reliable processes build trust.
Implement a standard data release process for data requesters not affiliated with a state agency.

The APCD statute defines two categories of organizations and individuals permitted to request APCD data access. The first category includes requests from communities, individuals, researchers, organizations, and private companies. These requesters will be subject to rules promulgated by the OHSC for access to and use of APCD data.

The Workgroups recommend a **standard data release process for data requesters not affiliated with a state agency** that includes the following steps:

1. The requestor completes a Data Request Application (DRA) in consultation with APCD staff.

2. The DRC reviews the application.
3. The DRC makes a recommendation to the Administrator on whether the requester should be granted data access.
4. The Administrator approves or denies the request.
5. If approved, a standardized data use agreement (DUA) is executed, and the requestor pays the appropriate fee.
6. The Administrator's staff processes the data request.

To ensure the DRC can adequately assess whether APCD data requests are consistent with the overall statutory intent of the APCD, and that the requestor has sufficient processes in place to protect the data, the Workgroups recommend that a Data Request Application minimally include:

1. the purpose of the request including a description of use that aligns with APCD statute
2. the specific data requested
3. a data management plan
4. an Institutional Review Board (IRB) approval (if necessary)
5. a statement on whether additional data releases will be needed and if so, the time frame(s)
6. plans for reporting findings.

If a data request is approved by the APCD Administrator, a standardized data use agreement (DUA) would be executed. The exact format and content of the DUA will be guided by the DUA Subgroup in the coming months.

**Recommendation #2b: Don't recreate the wheel if you don't need to.
Implement a standard data release process for state agencies utilizing
a memorandum of understanding (MOU).**

The second category of data requesting organizations defined by Georgia APCD statute is state agencies, including DCH, DPH, the Department of Behavioral Health and Developmental Disabilities (DBHDD), and other state agencies through the execution of memorandum of understanding (MOU) agreements after consultation with the Advisory Committee. Because this will result in the APCD having two different review processes for data release requests, the Workgroups' recommendation is offered as a two-part recommendation (2a and 2b).

The Workgroups recommend **a separate standard process for data release to state agencies:**

1. The state agency creates an MOU with the Administrator.
2. The Administrator will seek consultation from the Advisory Committee, if needed.
3. The DRC will review the MOU.
4. If there are no concerns, the Administrator approves and processes the request.

5. If there are concerns, the Administrator can consult with the state agency and Advisory Committee to determine the need for a revised approach.

Recommendation #3: Standards should be as standard as possible.

The provisions in state agency MOUs for releasing APCD data should closely mirror the requirements of the DUA for data requesters not affiliated with state agencies.

It is important that the content of an MOU for a state agency include most, if not all, of the DUA components and include anticipated uses of data. The Workgroups recommend the following provisions be included:

1. Allow the duration of an MOU to be between one and three years, with the ability for a state agency to easily renew the request if there are no changes to the content of the MOU. This would allow sufficient time for data analysis and will reduce paperwork for state agencies and the Administrator, over time.
2. Require an addendum if state contractors need APCD data for the purposes of conducting state agency projects and were not initially included in the MOU or if the state agency wants to use data for purposes outside of those originally outlined.
3. When universities request data for their own research, the process outlined in 2a would be followed. When a university is performing work on behalf of a state agency, the agency would follow the process outlined in 2b.

Recommendation #4: Promote the value.

Share results of APCD uses of data with the Data Review Committee

Georgia's APCD statute requires the Administrator to make available a listing of all requests for data, including whether the requestor was a state agency or private entity, the purpose of the project, and whether the data was approved for release. The Workgroups recommend that **researchers be required to share a summary of their results with the DRC**. This will enable the DRC to better understand the impact of using APCD data. Consideration will be given to the timing of sharing results if the results are being published.

Recommendation #5: Keep everyone informed.

Implement a process for the Administrator to provide regular reports to the Advisory Committee on the considerations of APCD data analysis, reports, or projects.

The statute provides that the Administrator of the APCD has the responsibility for collecting, aggregating, and distributing data for public and private health care purchasers and consumers, providers, and policymakers. It also provides that the Administrator will determine the reports and data to be made available to the public with recommendations from the advisory committee including conducting studies and reporting the results of the studies. There are numerous considerations that go into prioritizing the types of reports, studies, and analysis that will be conducted with APCD data. Identifying considerations such as the following will help the Administrator manage the portfolio of APCD data according to available resources:

1. data adequacy, sufficiency, or availability; purpose of the analysis
2. ability to produce actionable results
3. level of effort by the Administrator and staff
4. length of time required to conduct analysis, and the credibility of the individual or organization requesting analysis be done by the Administrator's staff.

The Workgroups recommend the **Administrator report on its portfolio of analytics activities to the Advisory Committee and OHSC on a quarterly basis.**