

Insights from Other States on Data Release Committees

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APCD Data Release in Action

- What perspectives do DRC members bring to the process?
- When does a DRC member have a conflict of interest?
- Hypothetical Request Scenarios

Data Release Committee Formation



	AR	DE	CO	CT	MA		N	OR	RI		VA	VT	WA
DRC Establishe in Rule	✓	✓	✓	✓		✓		✓			✓		✓
DRC Members Identified Rule		✓	✓		✓	✓	✓				✓		✓
DRC Appointed by Agency Head	B	✓	✓	✓	✓	B	✓	✓	✓	B	✓	B	

B: Identified by Board of Directors or Advisory Committee

Data Release Committee Members



- Most states specify committee member composition (10 of 13 states)
- Three states have state agency members only
- Among the other 10, most frequently named group representation
 - Hospitals (9)
 - Physicians, practitioners, providers (8)
 - Payers, insurers, carriers (8)
 - Researchers, nonprofits, quality organizations (8)
 - Consumers (7)
 - State agencies (6)

DRC Members' Expertise

- Members contribute insight from multiple areas of professional expertise
- In addition to their unique stakeholder perspective, members bring understanding of health care data, privacy and security
- Members often bring insight into data operations topics such as:
 - IT systems/technology
 - De-identification/PHI protection
 - Claims data processing
 - Clinician billing practices
 - Epidemiology and research

DRC Members Conflicts of Interest

Conflicts are not defined in regulation; business rules in two states address this

Colorado APCD DRRC Business Rules

Member shall declare any Conflict of Interest prior to Member's participation in any DRRC discussion of the affected APCD data release request, so the DRRC may determine whether Member should be excluded from such discussions or from advising the APCD Administrator, according to the DRRC Data Release Policies and Procedures.

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

Delaware HCCD [APCD] Business Rules

....b. Each Committee member is responsible for self-identifying a conflict of interest.

c. When a Committee member identifies a conflict of interest, the Committee member shall:

- i. Notify the Chairperson of the conflict as soon as possible, and at the latest at the start of the meeting during which the application will be reviewed.
- ii. Recuse him or herself from the application discussion, if the member feels his or her participation in the discussion will influence the voting process.
- iii. Recuse him or herself from voting on the application.

- <https://dhin.org/wp-content/uploads/2017/11/HCCD-Committee-Busines-Rules.pdf>

APCD DRC Hypotheticals

Hypothetical Data Release Criteria

- DRC role: Advise the administrator on whether the release of data is consistent with state law and rule
- Considerations
 - Is the requester a state agency or private entity engaged in health care improvement or other statutory purpose?
 - Is sensitive information needed, and if so, how it will be used?
 - Will the proposed use benefit state residents?

Hypothetical 1

A commercial entity requests, “A list of names and addresses of people in the Anytown metro area with a diagnosis of depression.”

To consider:

- Consistent with statutory purpose and rule
- Protects sensitive information
- Benefit to state residents

Hypothetical 1: Considerations

Request: “A list of names and addresses of people in the Anytown metro area with a diagnosis of depression.”

Staff screens application and determines:

- Request does not align with statutory purpose/rule
- Requires access to sensitive information that is not permitted
- Does not identify a benefit to state residents

Outcome:

- Based on merits, application is not forwarded for DRC Review
- Option to work with requester to develop a conforming request

Hypothetical 2

A community mental health center seeks data to build a strategic plan for serving the region's mental health and substance use disorder treatment needs. This will require data on access/use of services by care setting, prescription medications, primary diagnoses, trends, gaps in care and the effects of COVID-19.

To consider:

- Consistent with statutory purpose and rule
- Protects sensitive information
- Benefit to state residents

Hypothetical 2: Considerations

A community mental health center seeks data to build a strategic plan for meeting the region's mental health and substance use disorder treatment needs. This will require data on access/use of services by care setting, prescription medications, primary diagnoses, trends, gaps in care and the effects of COVID-19. Staff forwards application for DRC Review.

- DRC considers:
 - Statutory purpose/rule – Requestor is engaged in health care and improvement activities
 - Sensitive information – Analysis is possible without it
 - Benefit to state residents – Results can help improve access to care
- ***Outcome: DRC recommended access to data within the enclave***

Hypothetical 3

- A nonprofit research organization seeks five years of medical and pharmacy claims data for a national study examining variation in service utilization by children with diverse health care needs (e.g., physical, behavioral, neurodiversity). The request seeks a standalone file that includes indirect identifiers, e.g., dates of service and patient zip codes.

To consider:

- Consistent with statutory purpose and rule
- Protects sensitive information
- Benefit to state residents

Hypothetical 3: Considerations

A nonprofit research organization seeks five years of medical and pharmacy claims data for a national study examining variation in service utilization by children with diverse health care needs (e.g., physical, behavioral, neurodiversity). The request seeks a standalone file that includes indirect identifiers, e.g., dates of service and patient zip codes. Staff forwards for DRC review.

DRC Considers:

- Statutory purpose/rule – improve health care by understanding variation
- Sensitive information – large population, requires transmission of data files
- Benefit to state residents – needed clarification

Outcome: Conditional recommendation, contingent on revisions:

- Access within enclave or custom aggregated report without PHI
- Define relevant patient population, e.g., age, specific diagnoses; consider year of service, larger regions
- Clear statement of how results can benefit state residents