APCD Data Privacy & Security Subcommittee

Meeting #1 – April 26, 2019

Presented by: CedarBridge Group

Meeting Agenda

Agenda Item	Time
Welcome & Introductions	9:00 am
Public Comment	9:15 am
Overview of Subcommittee's Charge and Workplan	9:20 am
Environmental Scan	9:30 am
Next Steps	9:55 am

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The Support Team

State of Connecticut

Allan Hackney - Office of Health Strategy

Health Information Technology Officer

Rob Blundo – Access Health CT *(until 6/30/19)*

Director, Technical Operations & Analytics

CedarBridge Group

Carol Robinson

Michael Matthews, MPH

Chris Robinson

Mark Hetz, MBA

Dawn Bonder, JD

Introductions

Each member of the committee introduce yourself:

- ▫ Name
- ▫ Organization
- ▫ Any initial thoughts or concerns you have regarding use and release of APCD data

Members:
- ➢ Dr. Robert Scalettar (Chair) – RES Health Strategies / Access Health CT Board Member
- ➢ Ted Doolittle – Office of the Healthcare Advocate
- ➢ Matthew Katz – Connecticut State Medical Society
- ➢ Joshua Wojcik – Office of the State Comptroller
- ➢ Pat Checko – Representing the Data Release Committee
- ➢ Jean Rexford - Connecticut Center for Patient Safety
- ➢ James Iacobellis – Connecticut Hospital Association
- ➢ Bernie Inskeep – United Health Group
- ➢ Krista Cattanach – Aetna
- ➢ Dr. Victor Villagra – University of Connecticut Health, Health Disparities Institute

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Public Comment

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APCD Data Privacy & Security Subcommittee

➤ A review of applicable policies and procedures is required to ensure the incorporation of OHS' APCD requirements and strategy considerations.

➤ Subcommittee's initial charge is to review and comment on:
  - Existing APCD policies
  - APCD policy practices from other states
  - Current or anticipated concerns from data recipients, OHS staff, etc.
  - Define policy recommendations and next steps
  - Present recommendations to the APCD Council for review and affirmation

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Overview of Meeting Schedule / Workplan

Proposed Meeting Goal & Focus	Proposed Meeting Materials
Meeting #1 (April 26, 9am – 10am) – Kick-off and Orientation • Review and discuss project charter • Discuss proposed process/workplan for achieving desired outcomes • Orientation on Environmental Scan and current policies and procedures for data privacy / release	• Existing data privacy policies and procedures • Environmental Scan of other APCD initiatives
Meeting #2 (May 3, 9am – 10am) – Consider Current State of Data Privacy Policies • Evaluate current APCD data privacy policies • Consider new APCD policies to enhance program's effectiveness and efficiency	• Draft decision criteria • Evaluation matrix
Meeting #3 (May 17, 9am – 10am) – Consider Current Data Release Practices • Evaluate current data release policies and procedures • Consider new policies/procedures to enhance effectiveness and efficiency • Examine potential for APCD data to support approved use cases	• Existing data release policies and procedures
Meeting #4 (May 31, 9am – 10am) – Discuss Preliminary Recommendations	• Draft recommendations
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Overview of Environmental Scan

Online research

- Arkansas
- Connecticut ★
- Maine
- Massachusetts
- Minnesota
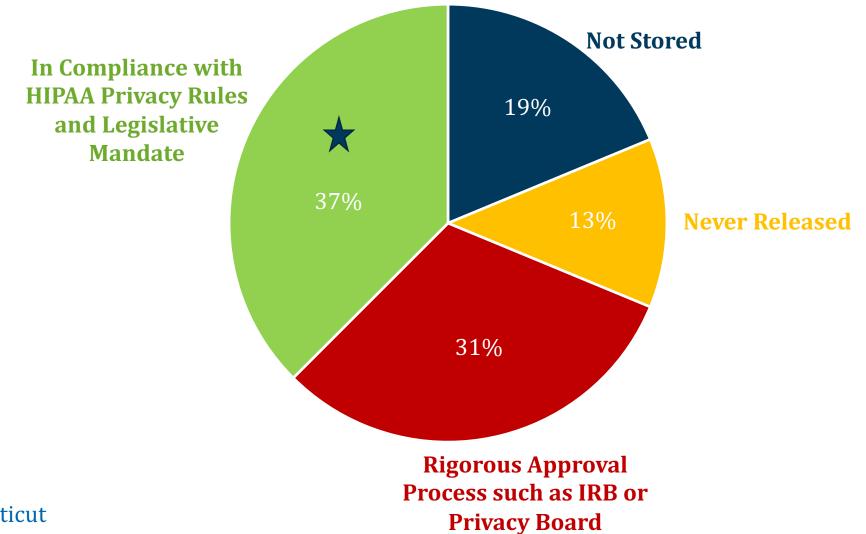- New York
- Rhode Island
- Utah
- Vermont
- Virginia

Telephone interview or e-mail response <u>and</u> online research

- Colorado
- Maryland
- New Hampshire
- Oregon
- Washington
- APCD Council
- National Association of Health Data Organizations (NAHDO)

Characteristics Assessed

➢ Treatment of Protected Health Information

➢ Data Release Governance

➢ Data Release Process

➢ Transparency of Data Request/Release

➢ Publication of Security Measures

➢ Consumer On-line Access to Data

➢ Treatment of Cost (Pricing) Data
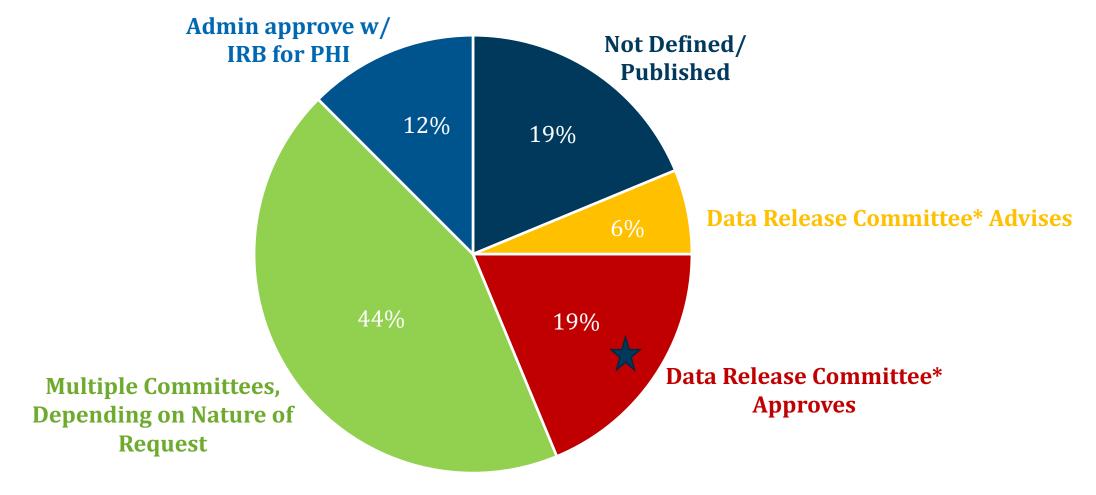
Treatment of Protected Health Information (PHI)

In Compliance with HIPAA Privacy Rules and Legislative Mandate — 37%

Not Stored — 19%

Never Released — 13%

Rigorous Approval Process such as IRB or Privacy Board — 31%

★ = Connecticut

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Trends and Observations:
Treatment of Protected Health Information (PHI)

➢ A state's ability to collect, store, and release PHI increases the value of an APCD program, and increases the ability of an APCD program to collect fees for releasing data to requesters for approved uses

➢ States that do not store PHI are not able to integrate claims data with data from other sources, impacting the overall value of the APCD program
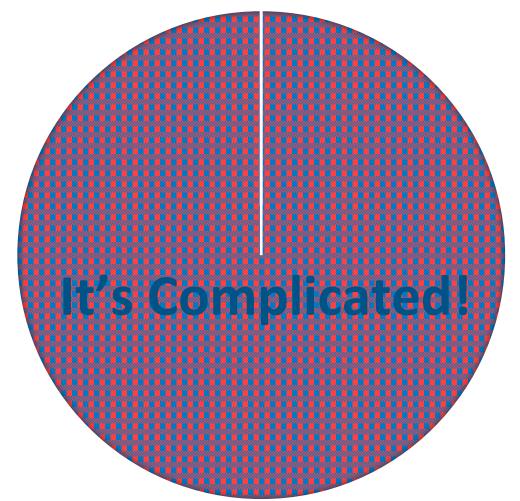
Data Release Governance

Admin approve w/ IRB for PHI — 12%

Not Defined/ Published — 19%

Data Release Committee* Advises — 6%

Data Release Committee* Approves — 19%

Multiple Committees, Depending on Nature of Request — 44%

★ = Connecticut

* Committee names vary by state

Trends and Observations:
Data Release Governance

➢ Governance of data releases by APCD programs vary widely depending on the type/complexity of data requests

➢ Some states are including stakeholders in the development of data release policies and/or in evaluating data requests by the APCD program

➢ Some states are moving to include IRB approval as a requirement for APCD programs to release PHI to data requesters
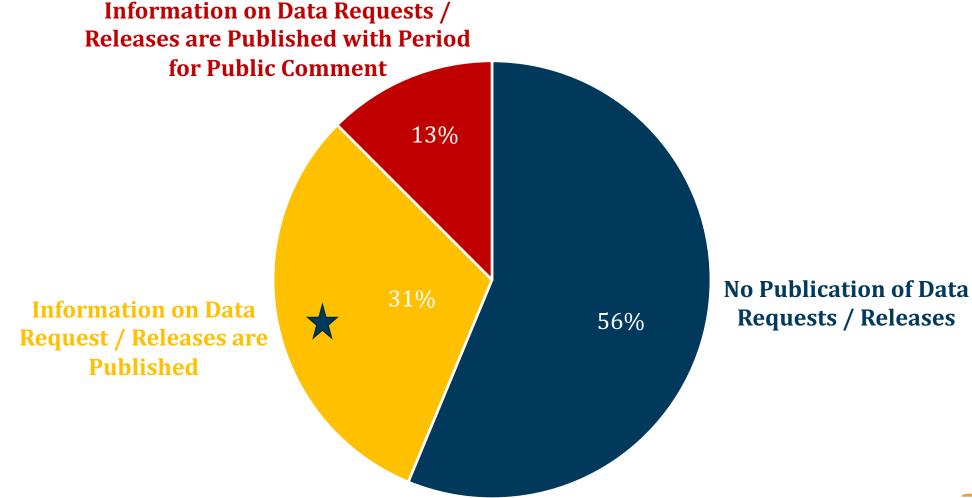
Data Release Processes

States Employ a Wide Variety of Processes for Evaluating/ Approving Data Release Requests

It's Complicated!

Trends and Observations:
Data Release Processes

➢ Some states are moving to streamline processes with online forms and pre-approved data sets for common purposes

➢ Some states are implementing iterative processes for data requesters to discuss data needs with APCD staff before making a data request to better understand availability of data and potential limitations, feasibility, etc.

➢ There are increasingly detailed data use agreements and required data management plans for data requesters

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Transparency of Data Request/Release

Information on Data Requests / Releases are Published with Period for Public Comment

13%

31%

56%

No Publication of Data Requests / Releases

Information on Data Request / Releases are Published

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* Some states exempt state agencies from publication of requests or releases

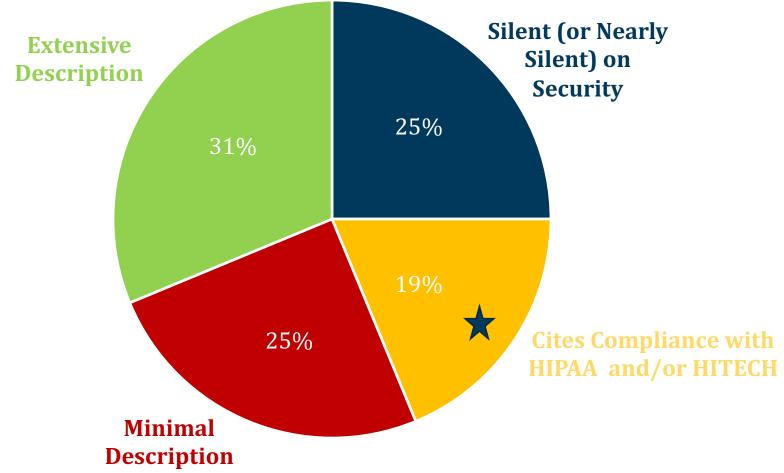OHS CONNECTICUT
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Trends and Observations:
Transparency of Data Request / Release

➢ States are trending toward providing more transparency around data requests and data releases

➢ Interviewees observed that transparency of data requests has reduced the frequency of "challenging" requests

➢ When states use a process to allow for public comments in advance of approving data requests, most comments come from healthcare organizations (payors or providers); very few comments are from consumers
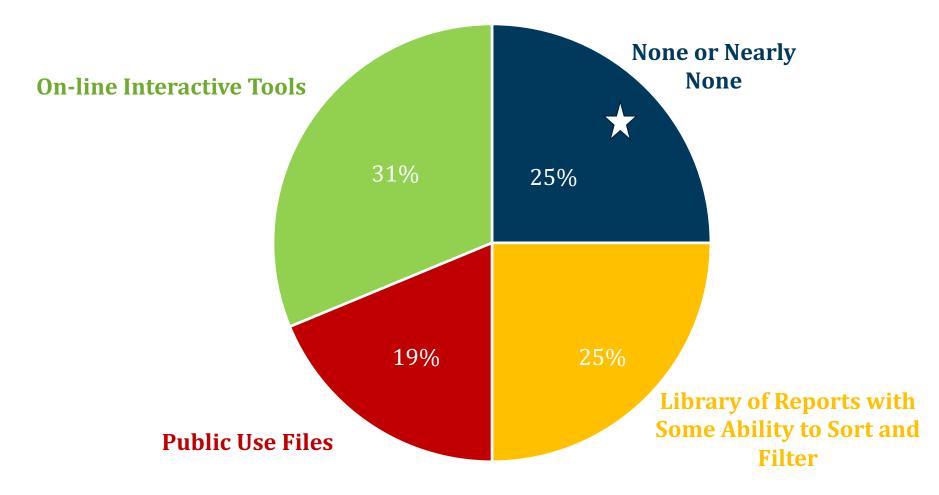
Publication of Security Measures

Pie chart:
- Silent (or Nearly Silent) on Security — 25%
- Cites Compliance with HIPAA and/or HITECH — 19% (★ = Connecticut)
- Minimal Description — 25%
- Extensive Description — 31%

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Trends and Observations:
Publication of Security Measures

➢ States are trending toward less specificity in their published materials about security measures employed by APCD programs; most cite adherence to industry standards and/or regulations

➢ This trend cuts across industries and is not limited to APCD programs or healthcare data systems

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Consumer Online Access to Data

On-line Interactive Tools — 31%

None or Nearly None — 25% ★

Library of Reports with Some Ability to Sort and Filter — 25%

Public Use Files — 19%

★ = Connecticut

Trends and Observations:
Consumer Online Access to Data

➢ Some states are providing interactive online tools for consumers to assess cost and quality of care offered by providers for specific procedures

➢ Some states have found that by providing prepared reports and a library of papers, data requests are reduced
  ▪ This could have an unintended consequence for program sustainability by reducing the collection of fees

Treatment of Cost/Pricing Data

APCD Legislative Mandate – Connecticut Public Act 13-247 (as amended by PA 18-91)

Enabled the Exchange's creation of the Connecticut All-Payer Claims Database ("APCD"). Pursuant to Public Act 13-247 (as amended by PA 18-91), various Data Submitters are required to report healthcare information to OHS for inclusion in the APCD.

This legislation allows OHS:

(i) to utilize healthcare information collected from Data Submitters **to provide healthcare consumers in Connecticut with information concerning the cost and quality of healthcare services that allows such consumers to make more informed healthcare decisions**; and

(ii) to disclose Data to state agencies, insurers, employers, healthcare providers, consumers, researchers and others for purposes of reviewing such Data as it relates to health care utilization, costs or quality of healthcare services.

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Trends and Observations:
Release of Cost/Pricing Data

➢States have begun to make cost/pricing data available to consumers

➢Efforts vary:
- Pre-prepared reports
- Regional reports with some customization possible through an interactive website
- Robust cost data by provider and procedure

➢Consumer usability varies across APCD program websites

➢Best efforts (CO, ME, NH, WA) offer robust data (cost and quality) on consumer-friendly, interactive websites that provide information consumers can use to make healthcare choices based upon cost and quality for specific healthcare procedures

Trends and Observations:
Treatment of Cost (Pricing) Data

➢ There appears to be a trend that over time, healthcare organizations become more accepting of the publishing of price data for specific procedures by an APCD program

- This is likely a result of building trust and of shared recognition of the value of the information

➢ Those states releasing pricing data to the public are doing so in a highly curated way to address payor/provider concerns, and also to help ensure the data is easily to understand and unlikely to be misconstrued by consumers

Additional Trends and Observations

- The environmental scan highlighted the need for states to be cognizant of the levels of stakeholder trust, confidence, and commitment to an APCD program

- Trust of stakeholders is essential in order to find consensus positions on data collection and on data availability for a variety of purposes
  - Trust in APCD data quality
  - Trust in accuracy of data reports from APCD program
  - Trust in the processes used to develop policies and procedures for the APCD program
  - Trust in the application of policies and procedures by the APCD program
  - Trust in the fairness of APCD data availability and data use policies and procedures

- As trust and confidence of stakeholders in an APCD program builds, new opportunities for expanding the use of APCD data can be considered

- As additional uses of APCD data are accepted by stakeholders, the value of APCD data will be more apparent, and support for funding of an APCD program will increase

Value = Sustainability

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Additional Topics to Explore

- Consumer access to APCD data

- Transparency regarding data requests and release

- Treatment of cost (pricing) data

- Best practices:
  - Improving data quality at the data source level
  - Ensuring accuracy of data reports
  - Governing APCD programs
    - Developing and monitoring policies and procedures
    - Considering new use cases for APCD program

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