

Getting Ready for CAA Section 115 APCD Grants

Elements of a Common Data Request Application

April 28, 2021



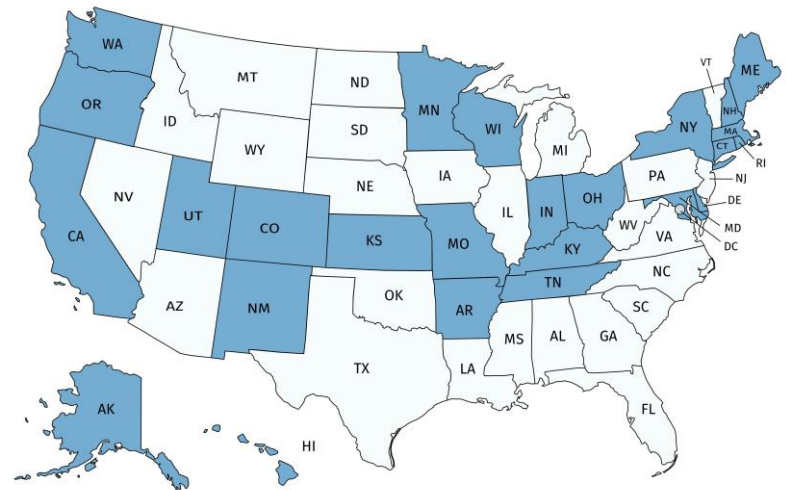
Linda Green
Jonathan Mathieu
Brian Boates

About Freedman HealthCare



- ▶ Founded in 2005
- ▶ Focus on government and nonprofit health data initiatives
- ▶ Experienced APCD managers and data analysts
- ▶ APCD “lifecyle” expertise: stakeholders, law, rule, RFPs, data quality, analytics, data access, sustainability

Freedman HealthCare States



Today's Presenters



Linda Green
Executive Vice
President



Jonathan
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Senior Consultant



Brian Boates
Project
Manager

National Association of Health Data Organizations (NAHDO)

NAHDO is a national non-profit membership and educational association dedicated to improving health care data collection and use.

NAHDO members include state and private health data organizations that maintain statewide health care databases and stakeholders of these databases.

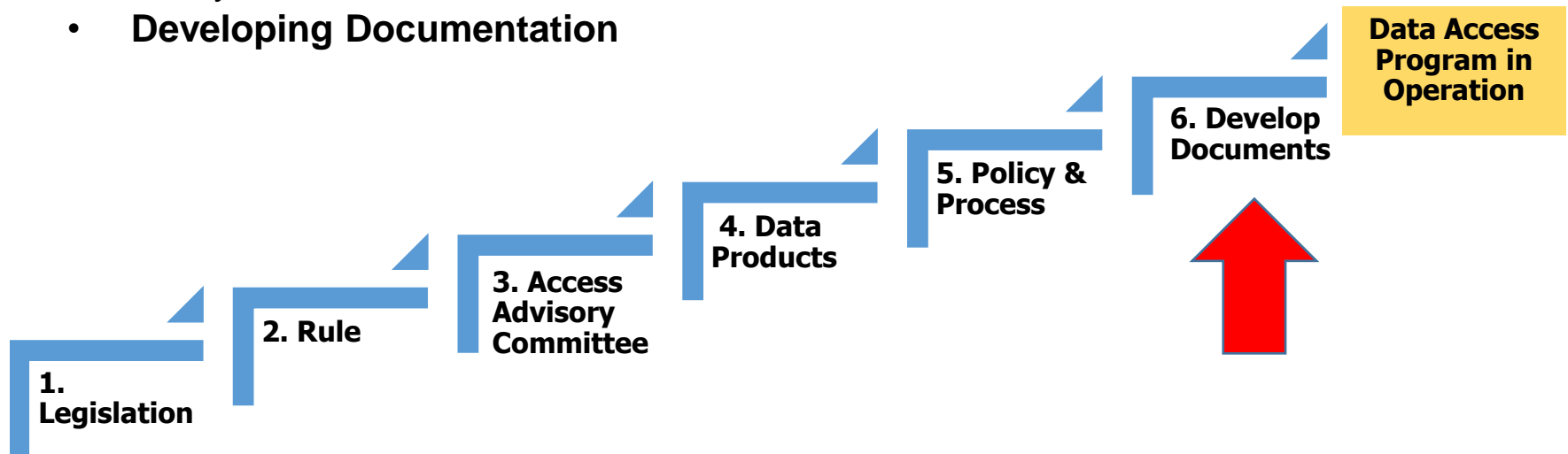
The APCD Council is a program of NAHDO in partnership with the Institute for Health Policy and Practice (IHPP) at the University of New Hampshire (UNH).



NAHDO.ORG & APCDCOUNCIL.ORG

Recap CAA Section 115 Data Access Requirements

- ▶ To be eligible for grants, State APCDs must have (or intend to have) a data access program
- ▶ Law offers guidance on:
 - Who must be allowed to request data
 - Purposes that must be supported
 - Types of data products
 - Policy & Process
 - **Developing Documentation**



Topics for Today's Webinar



- ▶ What does CAA Section 115 say about information and documentation required to access APCD data?
- ▶ What documents and best practices have APCDs developed to support their data access programs?
- ▶ How well do existing APCD practices align with CAA requirements?
- ▶ What additional documents have APCDs developed to support their data access programs?

The CAA and Data Request Documentation

- ▶ CAA Section 115 identifies three required documents

- ▶ **For Research:**
 1. **Application** describing the uses and methodologies for evaluating health system performance
 2. **IRB approval**, if applicable
 3. **Data Use & Confidentiality Agreement** including prohibitions on attempts to reidentify individuals and disclose IHI and proprietary financial information

- ▶ **For Other Uses** (Customized, non-Customized reports):
 4. **Application** describing the intended uses for the purpose of quality improvement or cost containment

- ▶ All three documents are consistent with existing APCD best practices

Best Practices – APCD Data Request Application



- ▶ Project Description/Purpose
 - Describes proposed data uses and analysis methods – consistent with CAA
 - Identifies specific research questions, hypotheses, goals, audience

- ▶ Data Requested
 - Describes necessary data elements, years of data, type of report
 - Requires justification for sensitive information – IIHI, PFI (prop. financial info.)

- ▶ Linkages to Other Data Sources (CAA doesn't address)
 - Generally limited to research and other advanced APCD uses

- ▶ Distribution of Results/Findings (CAA doesn't address)
 - How will results be shared, with whom, for what purposes

- ▶ Data Management
 - Data Storage, Access, and Destruction
 - Staffing, Physical, and Technical Safeguards

Best Practices – APCD Data Request Data Use Agreement (DUA)



- ▶ APCD DUA elements typically include:
 - Project personnel – Identifies individuals permitted to access the data and specific allowable uses
 - Description of data provided and limits on reuse, re-release or further disclosure
 - Project term/duration and provisions for contract termination
 - Provisions for data retention and destruction
 - Requirements for release of information products derived from the APCD data including Administrator prior review and approval
 - Prohibitions on re-identification of individuals and disclosure of IIHI and proprietary financial information – consistent with CAA

- ▶ Existing APCD DUAs would generally satisfy CAA Data Use & Confidentiality Agreement requirements

Other Materials to Support an APCD Data Request



- ▶ Data Request Process Overview
 - A step-by-step summary of the process to request APCD data.
 - Instructions for completing forms and how to get help.

- ▶ Data Dictionary
 - Comprehensive summary of the APCD data elements available for request and release.

- ▶ Data User Guide
 - Overview of the APCD – Data elements collected/available, validation processes, years of data
 - Summary information on data quality and completeness.

Questions Still Unanswered

1. What are the specific requirements and expectations for states working together to develop a common data request application?
2. What does application “priority” mean in practice?
3. Is there a hard limit of \$2.5 million per grant for each of the 50 states?
4. How and to what extent must data release criteria that currently differ across states be aligned to support a common data request application?

How to Get Started

Existing APCDs	<ul style="list-style-type: none">• Assess alignment of current data request materials with CAA Section 115 information, documentation and Data Use & Confidentiality Agreement requirements.• Determine necessary process and/or language changes to existing materials, then develop a plan, inclusive of a timeline.
APCDs in Development (Includes Voluntaries or entities contemplating an APCD)	<ul style="list-style-type: none">• Design data request materials to meet (minimum) requirements outlined in the CAA.• Engage APCD stakeholders and data providers for input on the data access program and request materials• Learn from existing APCDs and seek expert assistance.

APCD Data Release Resources



- ▶ [HealthFacts RI \(RI APCD\)](#)
- ▶ [Delaware Health Information Network \(DE HCCD\)](#)
- ▶ [Center for Improving Value in Health Care \(CO APCD\)](#)

Questions?

New Resources Available on FreedmanHealthCare.com



FHC's Resources page <https://freedmanhealthcare.com/data-resources/> , including:

- Your questions, answered: <https://freedmanhealthcare.com/wp-content/uploads/2017/11/CAA-APCD-Grant-Q-and-A.pdf>
- Find slides from our first four webinars:
 - [Getting Ready to Win Your State's Grant](#)
 - [Developing Data Access Programs](#)
 - [Data Product Types and Requirements](#)
 - [Protecting Individual Privacy and Reporting Financial Data](#)
- Pointers to best practices and sample materials
<https://freedmanhealthcare.com/wp-content/uploads/2017/11/APCD-Data-Access-Programs-What-to-Read.pdf>

Upcoming Webinars



- ▶ Upcoming in our Complimentary Webinar Series: Getting Ready for Federal Grants – all at 1 PM ET

May 12	Regional/Voluntary APCDs
May 26	Learning Community: Progress and Updates

- ▶ Sign up at

https://us02web.zoom.us/webinar/register/WN_UXLQHkLfRAuQDgbl_SthoQ