

Getting Ready for CAA Section 115 APCD Grants

Developing Data Access Programs

March 17, 2021



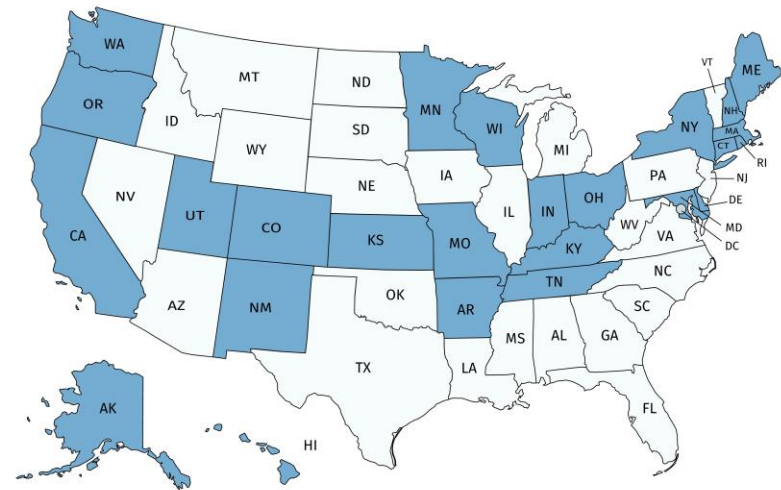
Jonathan Mathieu
Mary Jo Condon
Linda Green

About Freedman HealthCare



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

Freedman HealthCare States



Today's Webinar



- ▶ What are the Section 115 data access requirements?
- ▶ What is a typical APCD Data Access Program?
- ▶ Are my state's law and rule aligned with Section 115's requirements?

Today's Presenters



Mary Jo Condon
Senior
Consultant



Jonathan
Mathieu
Senior
Consultant



Linda Green
Executive Vice
President

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).



Recap CAA Section 115 Data Access Requirements



- ▶ To be eligible for grants, State APCDs must have (or intend to have) a data access process

- ▶ Law offers guidance on:
 - Who must be allowed to request data
 - Purposes that must be supported
 - The documentation to request access
 - Types of data products

- ▶ HHS Secretary can waive access requirements if APCD is “substantially in compliance.”

Data Products in CAA Section 115



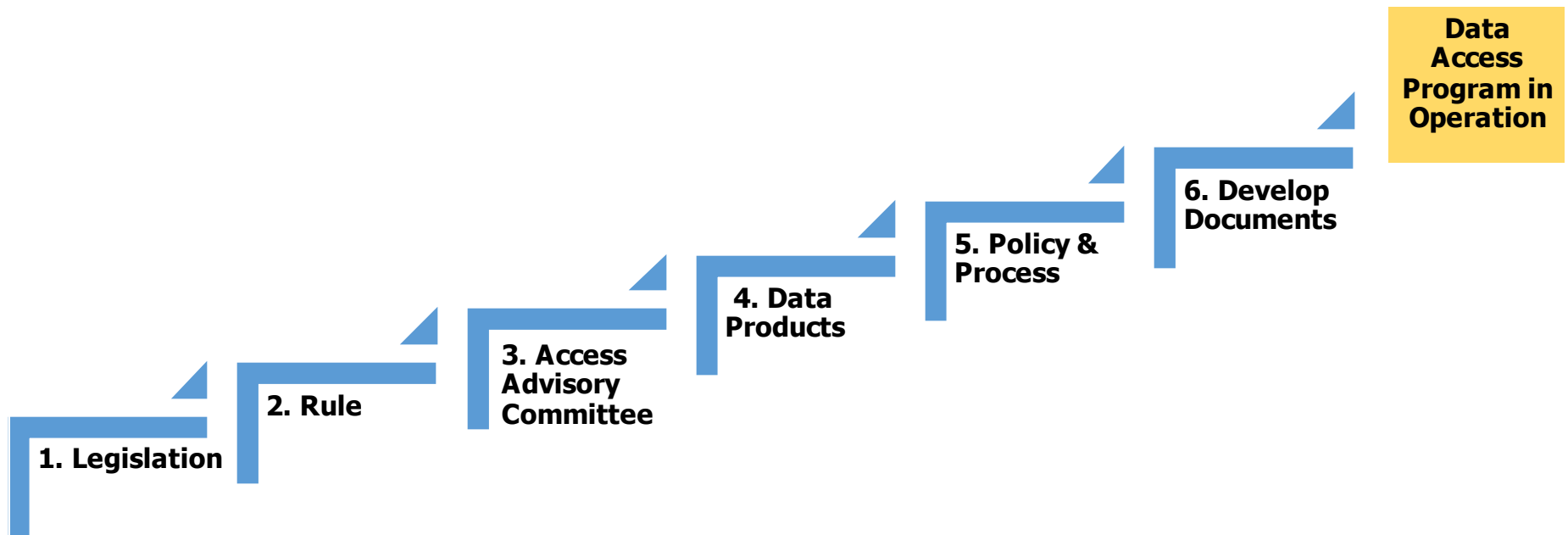
- ▶ Data for Research Purposes
 - Also known as Data Sets, Extracts
 - Public Use Files, De-Identified Data Sets?
 - Limited Data Sets, Identifiable Information?
 - CAA prohibitions on re-identification, PII, proprietary financial info

- ▶ Customized Reports
 - For (at least) employers and employer organizations – provided at cost
 - Format must protect data privacy/security, proprietary financial info

- ▶ Non-Customized Reports
 - Also known as Standard Reports, Public Reports
 - CAA specifies provided at no cost
 - Typically, summary statistics based on aggregated data, no PHI, no names
 - Could this include Public Use Files?

Typical Data Access Programs

Components of Data Access



▣ Legislation

- Directs APCD to make data available
- Designates agency responsible for fulfilling requests
- Often identifies categories of uses and users



▣ Regulation/rule

- Request process and user agreements
- Types of users and data that may be provided
- Role of stakeholder input/Advisory Committee
- Fee schedule

Data Access Advisory Committee



▣ Primary Purpose

➔ Review data requests and make recommendations ←

- May participate in data policy development

▣ Broad health care community representation

▣ Insight into

- Research methods
- Privacy, Healthcare data
- Data security management

Policy and Process Development



- ▶ Legislation and Rule establish broad parameters
- ▶ Responsible State Agency/Entity determines:
 - Who can access, for what purposes, under what conditions
 - What information is required, who makes decisions, how
 - Application and DUA Design, Internal workflows
 - May be advised by Data Access Committee
- ▶ Data Access/Advisory Committee provides essential multi-stakeholder insight and perspective

“Typical” Access Request Documents*



- ▶ Request/Application
 - Organization background, experience, personnel
 - Use cases/research questions, purpose, audience, goals
 - Data required, justification for PHI, “sensitive” information

- ▶ Data Use Agreement
 - How data can be used, results reported, no resharing
 - Privacy/security requirements, non-compliance penalties

- ▶ Data Management Plan
 - Recipient policies for protecting data privacy/security

*Plan to join us for more about CAA Section 115’s specific requirements during our April 28 webinar

Documentation Needs

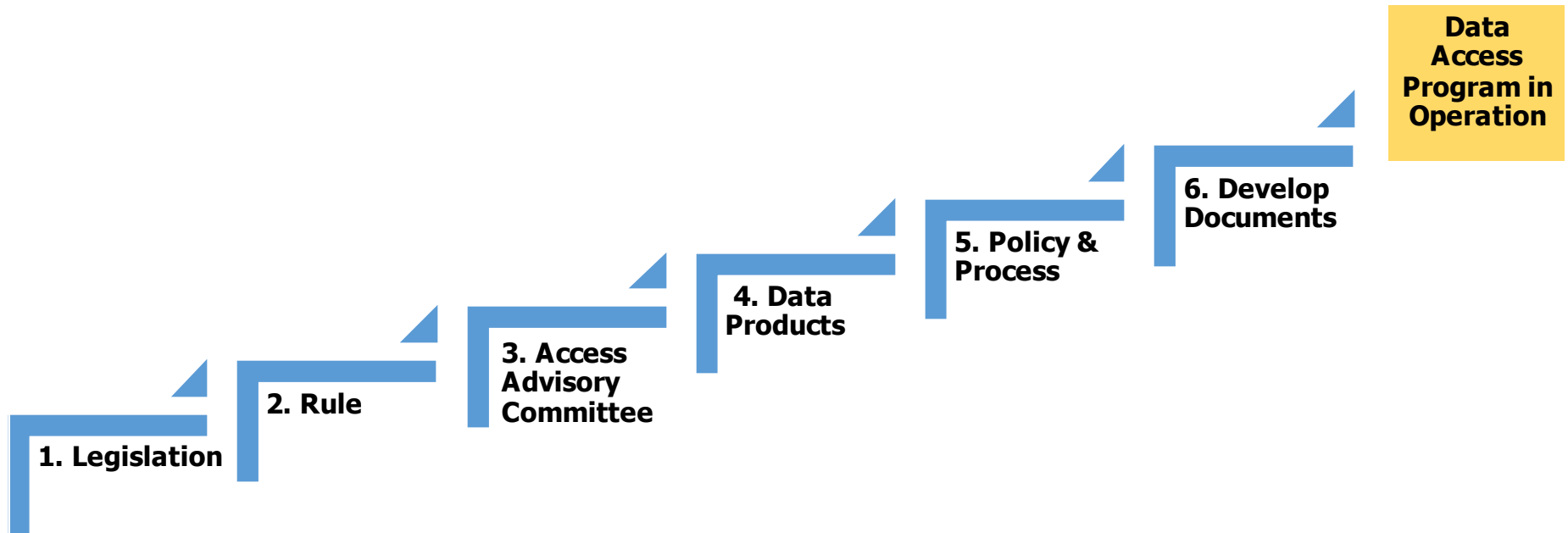
▶ Process Description

- “How to” of data access requests
- Who, what, under what conditions, authority, safeguards
- Timeline, Fees, Contact information

▶ About the Data

- What is included, what is not included
- Categories – Med and Rx claims, Eligibility, Provider info
- Field descriptions – plain language
- Log of known data quality issues, impacts, etc.
- Meta data and quality reports

Components of Data Access



Grant Application Readiness Checklist: Data Access



- Assess whether existing/planned statute *and* rule allow:
 - Researcher, Employer, Plan, TPA and Provider Access
 - Release of Data Sets, Custom and Non-Custom Reports
- ▣ Develop plan to pursue necessary changes
 - For mandated APCDs, law and rule
 - For voluntary APCDs, Board approval and data use agreements
- ▣ Convene or plan for Data Access Committee
 - Multi-stakeholder, diversity of perspectives
 - Healthcare data understanding and experience
 - Can assist with policy, process and document development
 - Review requests for compliance
- ▣ Conceptualize data products, fulfillment processes and fee schedule

Example Timeline

	2021		
	Q2	Q3	Q4
Assess if statute and rule (mandatory APCDs) or data use agreements (voluntary APCDs) meet requirements			
Develop plan to pursue necessary changes			
Convene or plan for Data Access Committee			
Conceptualize data products, fulfillment processes and fees			
Draft Grant Application			

Questions?

New Resources Available on FreedmanHealthCare.com



- ▶ APCD Data Access Programs – What to Read Next
- ▶ Coming soon: FAQ
- <https://freedmanhealthcare.com/data-resources/>

And any questions, please reach out:

Info@freedmanhealthcare.com

Upcoming Webinars

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

March 31	Data Product Types and Requirements
April 14	Protecting Individual Privacy and Reporting Financial Data
April 28	Elements of a “Common Data Request Application”
May 5	Regional/Voluntary APCDs
May 12	Learning Community: Progress and Updates

- ▶ Sign up at https://us02web.zoom.us/webinar/register/WN_UXLQHkLfRAuQDgbl_SthoQ

 Watch for our follow up email with slides and signup information