



DATA USE AGREEMENTS FOR PUBLIC HEALTH SURVEILLANCE:

AN INTRODUCTION FOR PUBLIC HEALTH PROGRAM MANAGERS



THE PUBLIC HEALTH LAW CENTER



EQUALITY:

Everyone gets the same – regardless if it's needed or right for them.



EQUITY:

Everyone gets what they need – understanding the barriers, circumstances, and conditions.



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based on work for First Nations Health Authority at Gathering Wisdom VI Drawing
change

Image credit: Sam Bradd <https://drawingchange.com/gathering-wisdom-visuals-for-a-healthy-future/>

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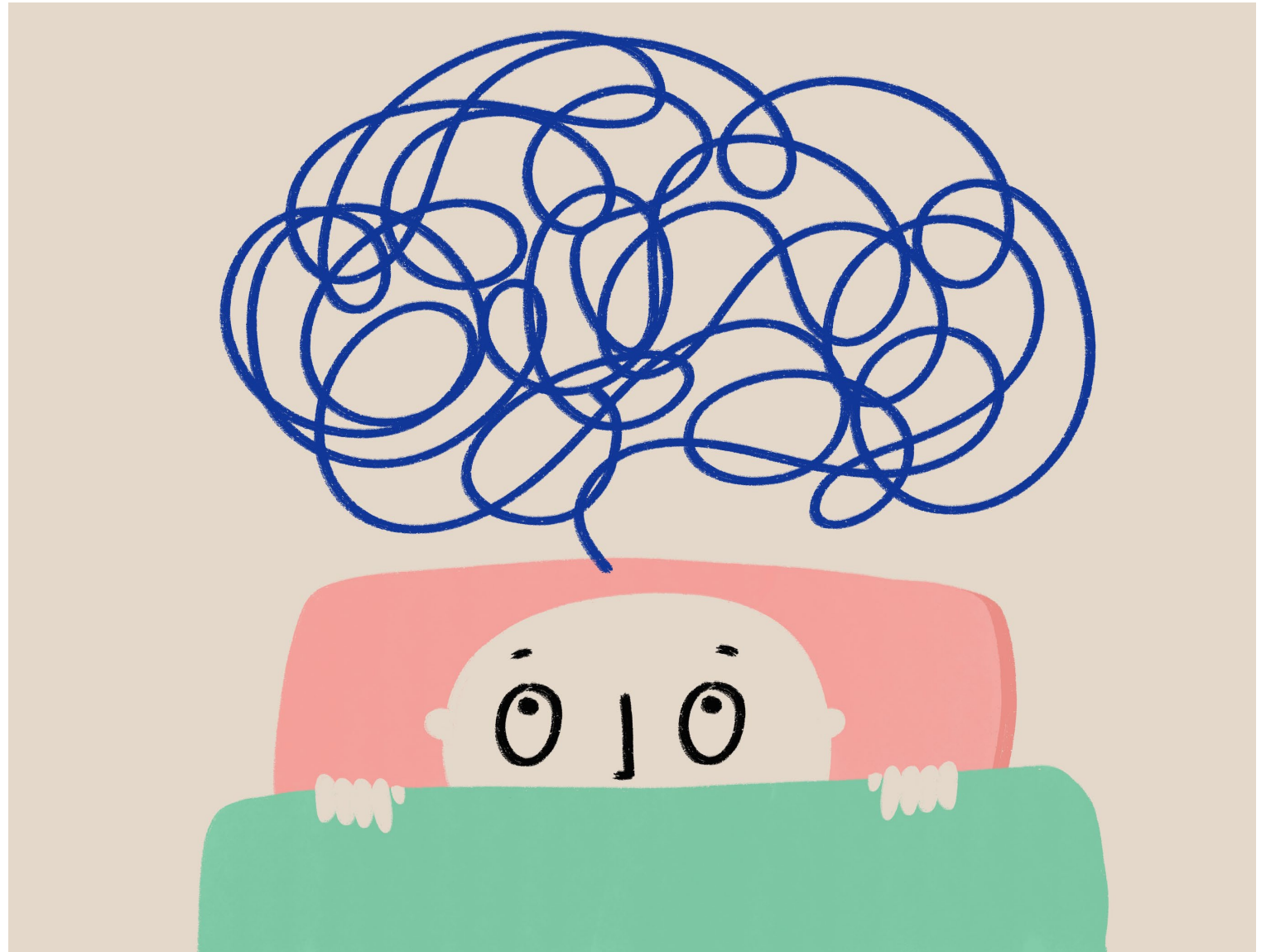


COLLABORATION WITH THE COUNCIL OF STATE AND TERRITORIAL EPIDEMIOLOGISTS (CSTE)

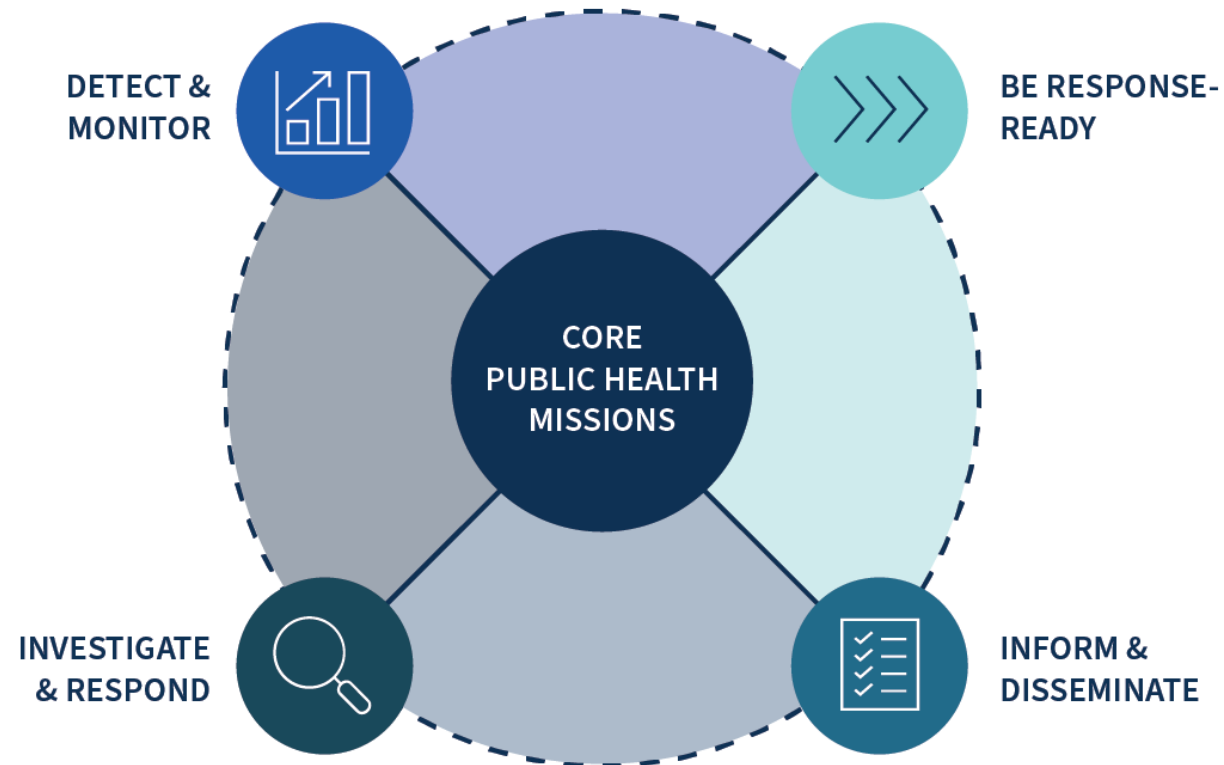


- PHLC
 - Providing legal and policy research
 - Developing resources
 - Conducting trainings
- CSTE
 - Conducting an assessment of barriers to data sharing
 - Preparing resource repository
 - Sharing resources with their members

WHAT DOES IT ALL MEAN?



WHY DO HEALTH DEPARTMENTS SHARE DATA?



ELEMENTS OF DATA GOVERNANCE

ELEMENTS OF DATA GOVERNANCE

WHAT IS IT?

- "Is it Legal?"
- Legal is one piece of the puzzle



ELEMENTS OF DATA GOVERNANCE

WHAT IS IT?

- Definitions
 - Data governance represents “a **set of processes, policies and practices that ensure** an organization’s structured **data is regulation-compliant throughout its lifecycle** by assessing its quality, security and accessibility,” ([source](#))
 - “**Data governance is the people, policies, and procedures that support how data are used and protected.**” ([Actionable Intelligence for Social Policy resource](#)) (AISP)

ELEMENTS OF DATA GOVERNANCE

WHAT IS IT?



- Iterative process that guides a project or data through its life cycle ([AISP resource](#))
- Considerations:
 - Collection
 - Use and/or Disclosure
 - Storage
 - Security
 - Maintenance
 - Integration
 - Destruction

ELEMENTS OF DATA GOVERNANCE

WHAT IS IT?

- Involves multiple parties and/or roles
- Multidisciplinary team
 - Data owner
 - Data stewards
 - Data custodian
 - Others



ELEMENTS OF DATA GOVERNANCE

WHAT IS IT?

- Not just a legal or compliance effort
- Data governance goals:
 - Better analytics and decision making
 - Build standard, repeatable processes
 - Adopt common approaches across programs or agencies
 - Transparency
 - Trust

Colorado data modernization: Assessment to action

CONTRIBUTOR: *Paul Gillenwater, Communicable Disease Technology Manager, Colorado Department of Public Health and Environment*

CATEGORY: **Epidemiology and Laboratory Capacity (ELC)**

CATEGORY: **Enterprise Approach to Data Systems Modernization**

To meet the public health response needs, including case reporting and contact tracing, the Colorado Department of Public Health and Environment (CDPHE) had to invest significant time and resources to enhance old systems, integrate data between systems, and develop new solutions for case management and data sharing.

[CSTE Stories from the Field - CO](#)

WHAT IS A DATA USE AGREEMENT?

- A legally binding document outlining the terms and conditions for sharing and using sensitive data
- In the public health context, the data typically includes protected health information



TYPES OF AGREEMENTS: ALPHABET SOUP



- Business Associate Agreement (BAA)
- Memorandum of Understanding (MOU)
- Data Use Agreement (DUA)
- Data Sharing Agreement (DSA)

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HOW LONG DOES IT TAKE TO EXECUTE A DATA SHARING AGREEMENT?



- For the chat: What are the pain points in the process that slow things down?

DATA USE AGREEMENTS: COMMON TERMS (1)

- Legal Authorities (Laws)
- Permitted Uses & Disclosures
 - Specific Purpose
 - No Re-identification
 - Access Limitations



DATA USE AGREEMENTS COMMON TERMS (2)



Safeguards & Security

- Data Security
- Data Integrity
- Data Storage

DATA USE AGREEMENTS: COMMON TERMS (3)



- Reporting and Accountability
 - Reporting violations
 - Auditing
 - Accountability

DATA USE AGREEMENTS: COMMON TERMS (4)

- Other Issues
 - Data Ownership
 - Term of the agreement
 - Termination
 - Publication



WHAT HAVE WE MISSED?

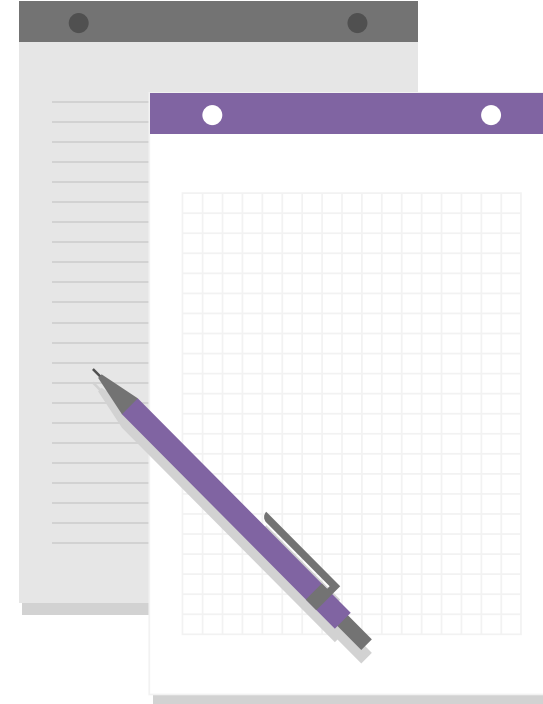
WHAT WOULD YOU LIKE TO KNOW MORE ABOUT?

- Legal Authorities
- Permitted Uses and Disclosures
- Access Limitations
- Data Security and Storage
- Safeguards To Protect Unauthorized Use and Disclosure
- Assurance that the Accuracy and Integrity of the Data Is Maintained
- Data Security
- Data Destruction
- Reporting and Accountability
- Data Ownership
- Data Sharing
- Term And Termination
- Intellectual Property

WHEN DO YOU NEED A DUA FOR PUBLIC HEALTH DATA SHARING?

WHEN DO YOU NEED A DUA?

- DUAs are generally used with individuals or entities *outside* of the health department
- DUA may not be *legally* required
 - Laws often do not specify the terms and conditions for data sharing or may only specify the purposes for which data may be disclosed
- DUAs are a best practice
- Data governance policies and procedures can help ensure consistency



WHEN DO YOU NEED A DUA?

CONSIDERATIONS



- Each **use case** has a specific purpose, type of data exchanged, and rules for interactions between people and systems
 - Specific business, technical, and legal frameworks

WHEN DO YOU NEED A DUA?

CONSIDERATIONS

- Who, What, Why, When, How of a data sharing request
 - Who is receiving the data?
 - Data to be shared
 - Program source (surveillance, HIV, vital records, etc.)
 - Identifiable, aggregate, de-identified, limited data set?
 - Purpose and goals
 - On-going or one-time?
 - Technical and security aspects



WHEN DO YOU NEED A DUA?

CONSIDERATIONS

- What laws apply?
 - HIPAA
 - 42 CFR 2
 - Common Rule
 - State public health laws
 - State privacy laws
- Save the date for our next webinar:
 - May 21st



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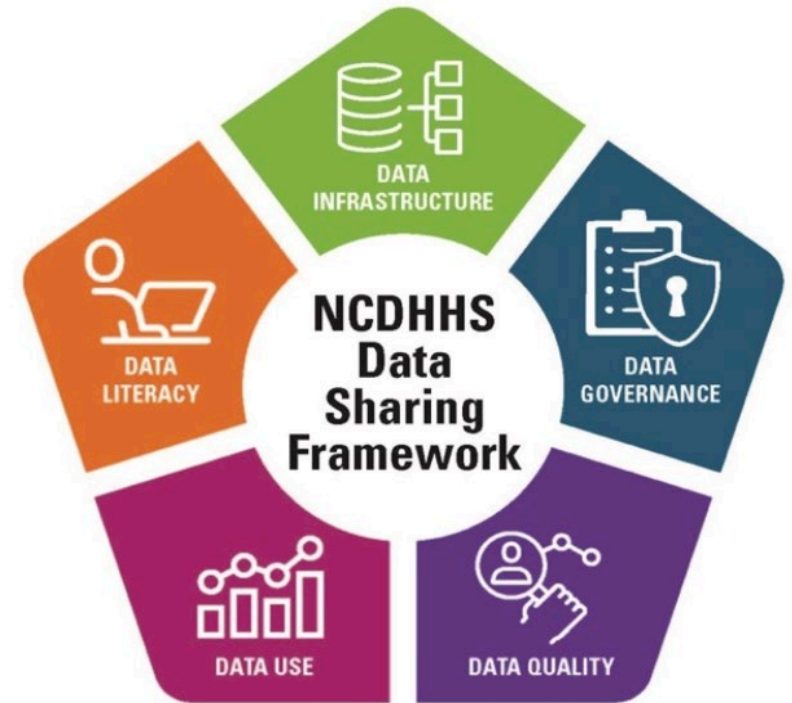
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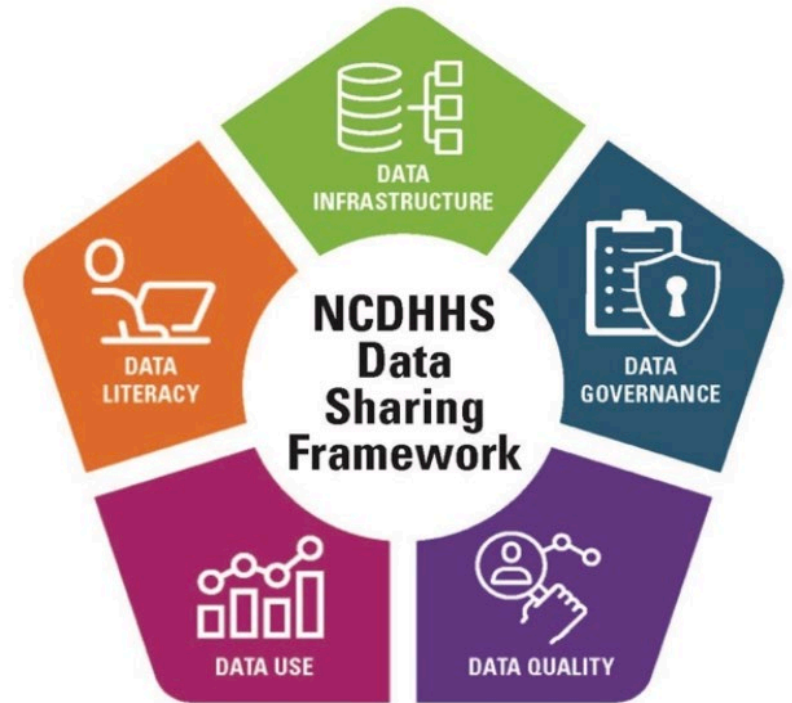
- In addition to legal and DUA questions:
 - What are your health department's policies and procedures?
 - Resources?
 - Priorities?
 - Goals?



ELEMENTS OF DATA GOVERNANCE

WHAT IS IT?

- The Why of Data Governance
 - Establish clear pathways for data sharing and integration
 - Establish a common legal framework
 - Support data use to improve data quality, insights, and improvements
 - Clarify processes to reduce staff burden, increase efficiency, and ensure privacy and security



ELEMENTS OF DATA GOVERNANCE

HOW DO DATA USE AGREEMENTS FIT IN?

- Best practice to document data sharing relationship, legal and other requirements
 - Not *a/ways* required or needed
- Typically, attorneys involved in policy and legal review of proposed data sharing
 - Assess legality and requirements in tandem with organizational practices and procedures
- Attorney as part of the team – bring in early and often!



LEGAL TECHNICAL ASSISTANCE

-  Legal Research
-  Policy Development, Implementation, Defense
-  Publications
-  Trainings
-  Direct Representation
-  Lobby

QUESTIONS?



RESOURCES ON DATA SHARING

- [Public Health Law Center's Data Sharing Toolkit](#)
- [Network for Public Health Law's Resources on Health Information and Data Sharing](#)
- [NPHL's checklist of information needed to address proposed data collection access and sharing](#)
- [American Indian Health Commission's Data Sharing Resources:](#)
 - [AIHC's Checklist for Use by State and Tribal Nations](#)
 - [AIHC's Model Tribal Data Sharing Agreement](#)
- [CSTE Brief: Enhancing Data Access to Improve American Indian and Alaska Native Health: A Framework for State and Local Public Health Officials](#)

RESOURCES ON DATA GOVERNANCE

- [Data Governance: What it is and how it enhances data management](#)
- [ONC Data Governance Framework](#)
- [AISP's Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration](#)
- [NPHL Data Governance Strategies for States and Tribal Nations](#)
- [ASTHO Brief: Policy Options to Improve Data Sharing Between State and Local Health](#)

[Departments](#)

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