

State Health Departments and Tribes: A New Public Health Data Sharing Approach and Model

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Wednesday, September 17, 2025

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SPEAKERS

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is an attorney who provides legal and management consulting services to non-profits and governmental agencies in the public health arena. Her areas of expertise include health data privacy laws and legal issues around Tribal Epidemiology Centers' and Tribes' access to health data from federal, state, and local public health agencies. Previously she was a Deputy Director at the Network for Public Health Law, and held other positions as a HIPAA Privacy Officer, legal services attorney, and community organizer.
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PETER RECKMEYER, ESQ.

is the Deputy General Counsel at the Alaska Native Tribal Health Consortium, a tribal health organization located in Anchorage, Alaska. He has over 20 years of experience working in-house. Mr. Reckmeyer's areas of expertise include M&A transactions, software license agreements, data use agreements, and other contractual arrangements.

Not Legal Advice

Nothing offered in this presentation is legal advice, should be relied upon as advice. When the history of legal advice will not appear, as it is not legal advice tonight what you learned at work tonight legal advice, Mom!", followed by what information you wish to give, which, relevant and helpful to your work, is,



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Project Team

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Alaska Division of Public Health



BACKGROUND

- **State legal authority to disclose health data**
- **Tribal epidemiology centers**



**TRIBAL
EPIDEMIOLOGY
CENTERS**

BACKGROUND - ANTHC

- **Operates statewide hospital for Alaska Native people**
- **Performs IHS's statewide public health responsibilities in Alaska. Indian Self-Determination and Education Assistance Act ("ISDEAA") transferred IHS's public health responsibilities to ANTHC**
- **Includes the Alaska Native Epidemiology Center ("Epi-Center"). Epi-Center NOT a separate legal entity**

The Problem



ANTHC'S PERSPECTIVE ON BARRIERS

Obstacles to Accessing Data:

- 1. ANTHC not recognized as a federal public health authority.**
- 2. Different data use agreements for each data system**
- 3. Different views of the minimum necessary rule**
- 4. Lack of trust in how data would be used**

1. ANTHC Not Recognized as Federal Public Health Authority

- **Not informed about federal legal authorities**
- **Not aware of ANTHC's roles and responsibilities**
- **ANTHC's organizational structure was a mystery**
- **Considered Epi-Center an independent entity**

2. Different Forms and Terms for Each Data System

- **Lack of standardized terms**
- **Agreements set up for individuals rather than for legal entity**
- **Data disclosed to individuals**
- **ANTHC's public health employees excluded from access**
- **Short term agreements**

3. Different Views on “Minimum Necessary” Rule

Law permits:

- disclosure of PHI to public health authorities for public health purposes
- Alaska law requires DPH to disclose minimum necessary to accomplish purpose of disclosure.
- HIPAA permits DPH to reasonably rely on ANTHC's representation that requested data is the minimum necessary for public health purposes.

Reality:

- DPH did not rely on ANTHC's representations
- DPH pushed back on scope of data requested
- DPH required specific use cases

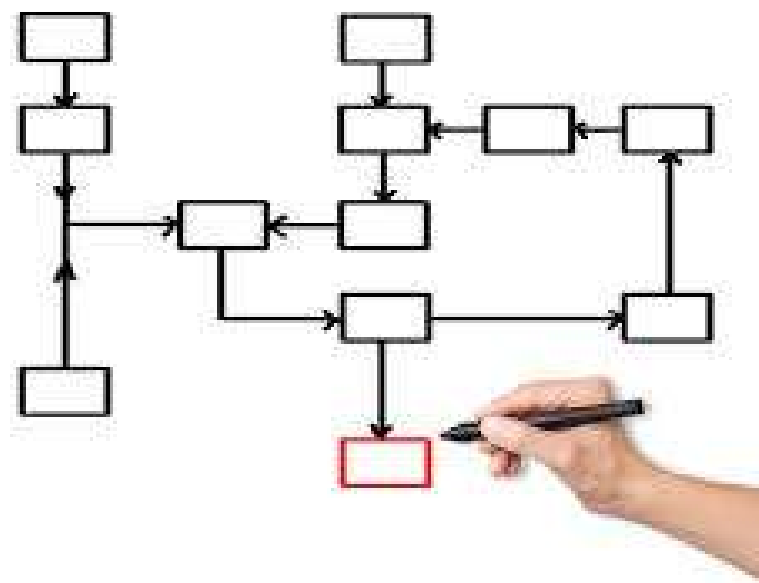
4. Lack of Trust

- **Did not trust how ANTHC would use the data**
- **Did not trust who would access the data**
- **Did not respect judgement ANTHC's public health professionals**

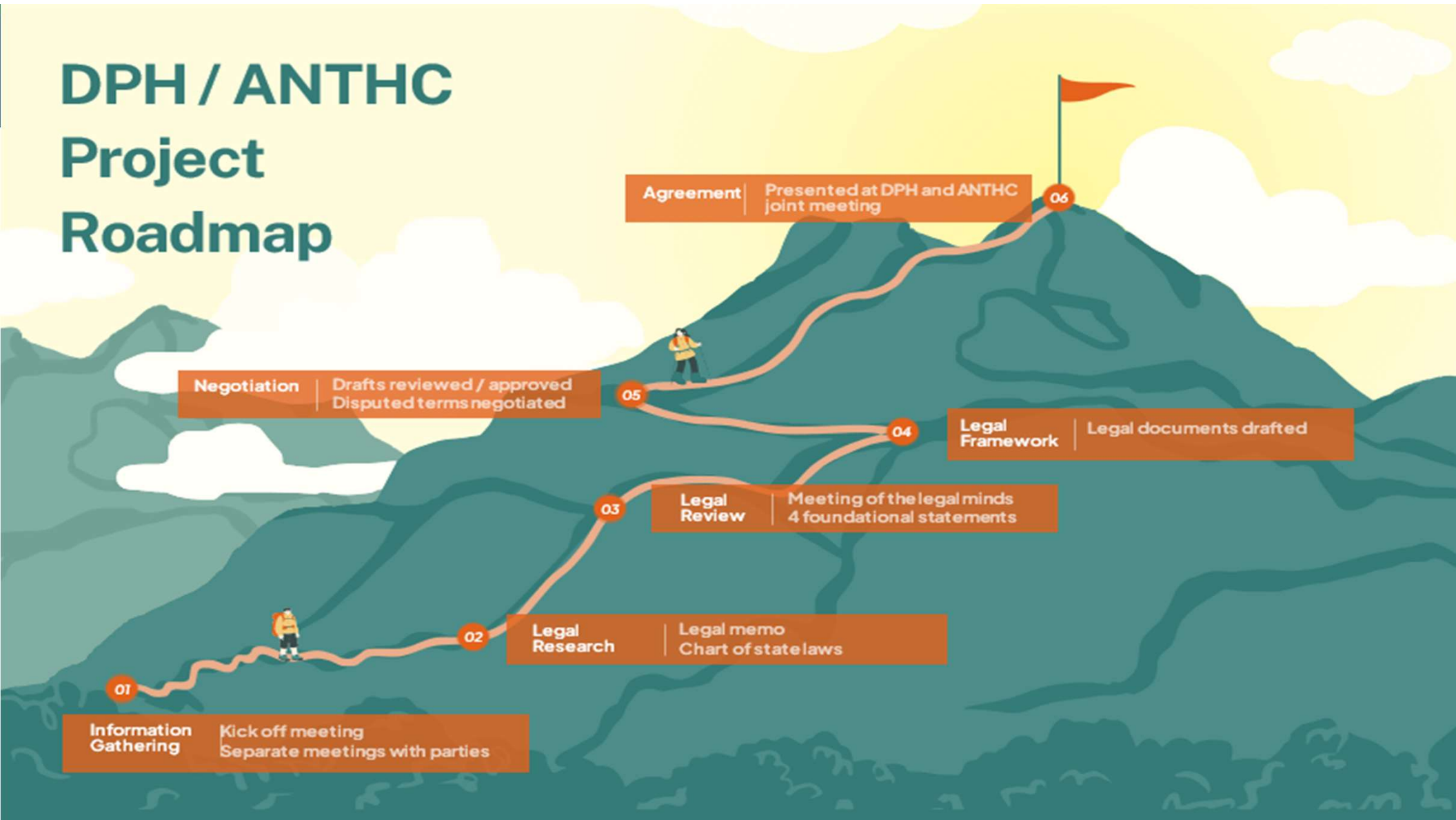
CONSULTANT'S PERSPECTIVE ON BARRIERS

- **Lack of a policy**
- **Decentralized DPH decision making**
- **No meeting of the minds of ANTHC's public health status or authority**
- **ANTHC's organizational structure not clear to DPH**
- **Limited DPH legal resources**
- **Past experiences negatively impacted new requests**

The Process



DPH / ANTHC Project Roadmap



ANTHC'S View: The Legal Memo

- **Focused the Attorneys on unsettled issues**
- **Provided legal basis for ANTHC as a public health authority**
- **Identified state laws restricting DPH's disclosures**
- **Harmonized minimum necessary standard under HIPAA and state law**

4 Foundational Statements

- Legal authority of ANTHC's Epi Center to function as a public health authority under 25 USC1621(m)
- Legal authority of the ANTHC to function as a federal public health authority under IHS's transfer of its state-wide programs, functions, services and activities to the ANTHC
- ANTHC's and Epi Center's authority under HIPAA to receive data, including PHI, from DPH for public health purposes
- DPH may reasonably rely on the ANTHC's representation that the data it is requesting is the minimum necessary for the public health purpose the data is requested.

ANTHC'S View: Four Foundational Statements

Step critical for understanding DPH's hang ups.

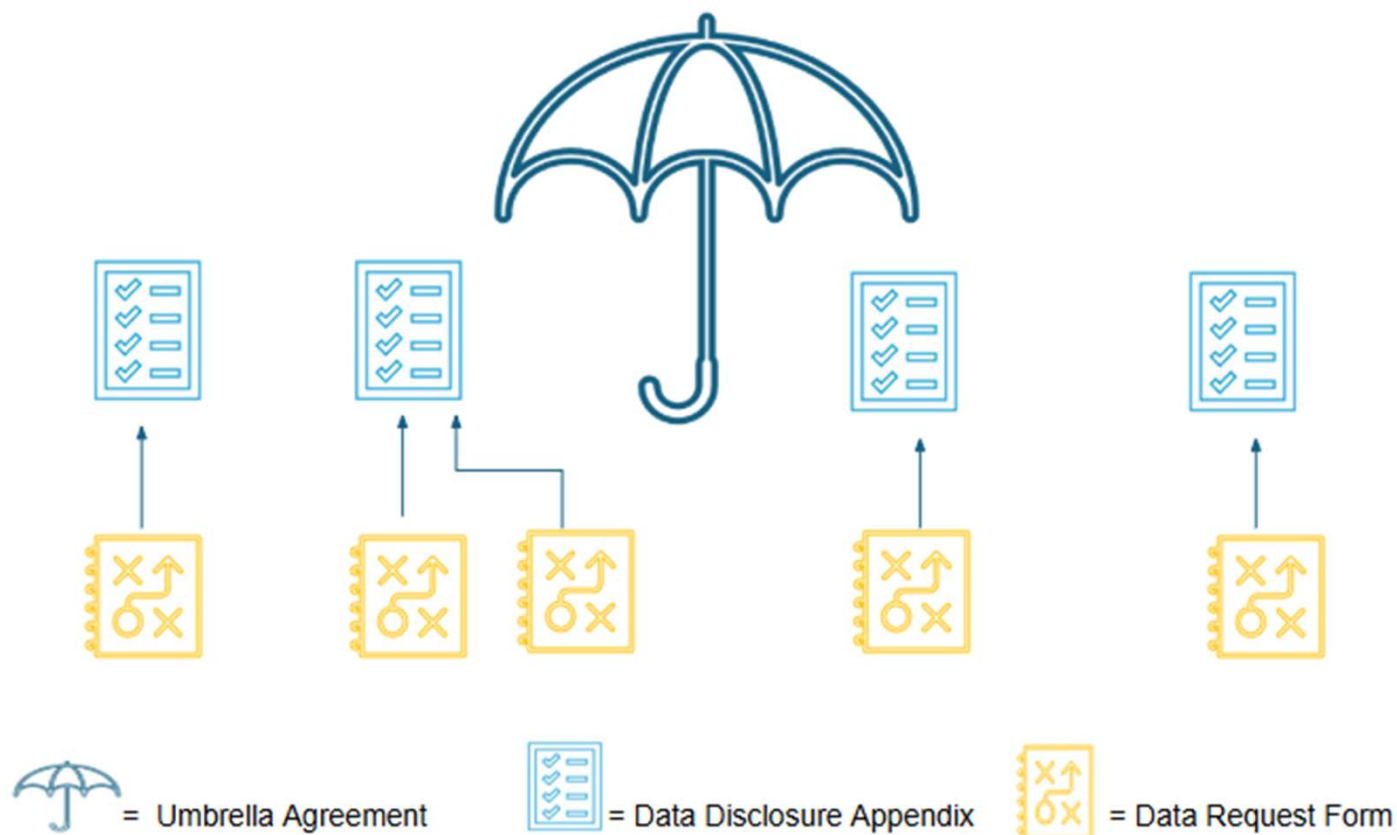
- **Understood Epi Center as a public health authority.**
- **Did not understand ANTHC's public health sector**
- **Did not understand ANTHC org structure**
- **Did not trust scope of data requested**
- **Feared violating state laws**

ANTHC'S View: DPH Education on ANTHC needed

- **Provided legal documents underlying legal authorities**
- **Presented live tutorial session on history of Alaska Tribal Health System**
- **Identified ANTHC's public sector programs**
- **Shared the Epi-Center's interactive dashboard and ANTHC's use cases and data sources for ANTHC publications**

Legal Framework





Suite of Documents

- Umbrella Public Health Data Agreement
- Data Disclosure Appendix
- Data Request Form

Umbrella Public Health Data Agreement

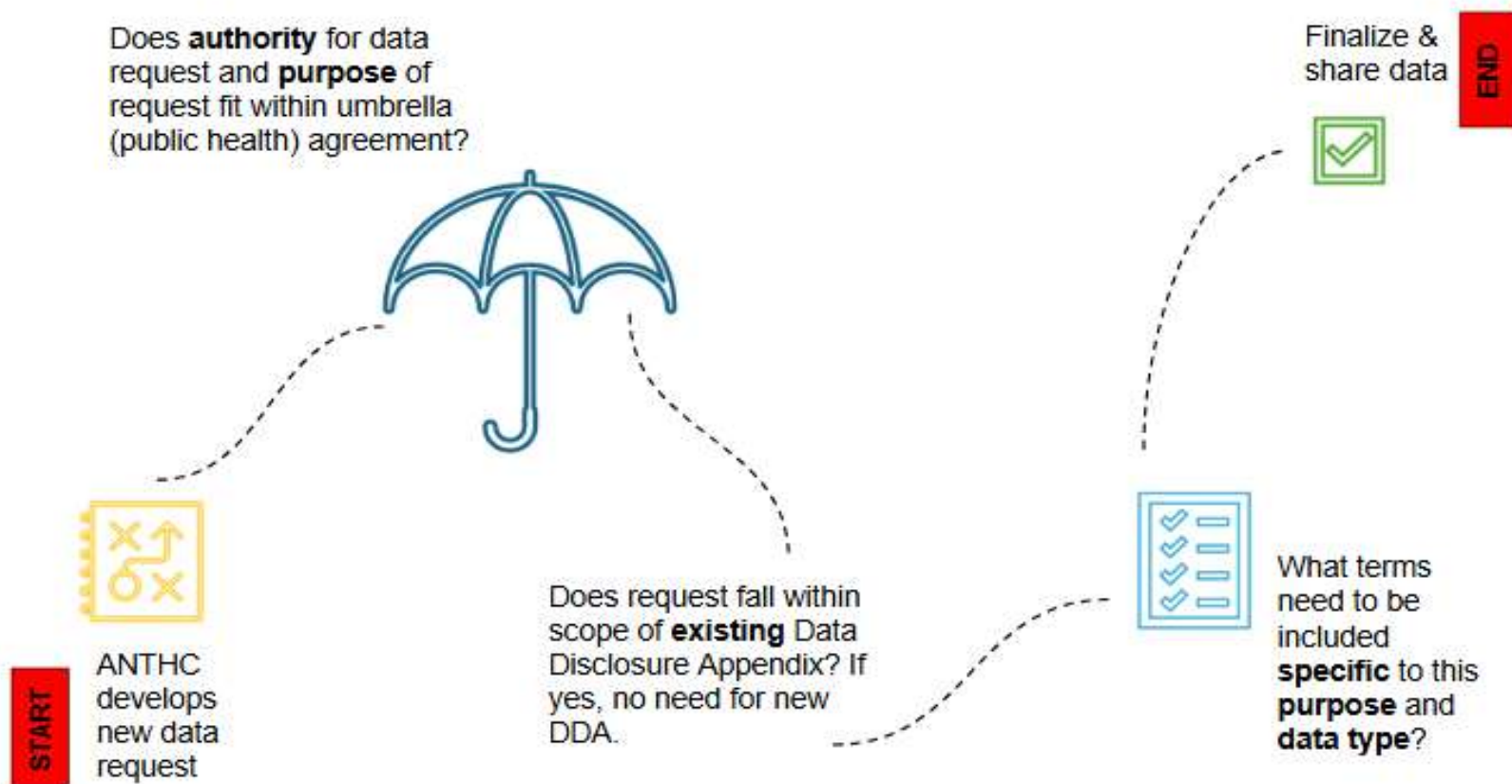
- Key principles recognized in Agreement
- Legal authorities
- Parameters for permitted uses and disclosures
- No expiration date; can be terminated per terms
- Review every 5 years
- Does not supersede or nullify existing agreements

Data Request Form

- Purpose of the Data Disclosure Appendix (DDA)
- Applicable Law
- Format of the Data to be Disclosed
- Data Elements
- Permitted Uses and Disclosures
- Frequency of Disclosure

Data Disclosure Appendix (DDA)

- Purpose of the DDA
- Applicable Law
- Format of the Data to be Disclosed
- Data Elements
- Permitted Uses and Disclosures
- Frequency of Disclosure
- Any additional Terms



ANTHC'S View: Breaking Ground on Umbrella Agreement

- **Identified standard provisions**
- **Included applicable legal authorities**
- **Acknowledged ANTHC and Epi Center's status as a public health authority**
- **Included standard permitted uses and disclosures**
- **Negotiated standard terms for disclosing individually identified data and limited data sets**
- **Acknowledged DPH may rely on ANTHC's minimum necessary representations.**
- **Agreed patient consent is not needed for sharing data to public health authorities.**

ANTHC'S View: New Structured Arrangement

The Umbrella Agreement resolves each barrier:

- Recognizes ANTHC and Epi-Center as
- Not all public health done
- One agreement
- Greater consistency

Center with more consistency – fewer hiccups!

a better understanding of ANTHC and its role in public health,
DPH now trusts how ANTHC will use the data

The Outcomes



ANTHC's View

4 Appendices Finalized Since January 1, 2025

- **ANTHC had no issues completing each Data Request Form**
- **Quick turnaround time for each Data Disclosure Appendix**
- **Each Appendix signed with no fuss**
- **Process completed in weeks rather than months**

Consultant's View

DPH now shares more public health data with ANTHC:

- ✓ **Faster**
- ✓ **Applying consistent standards and criteria**
- ✓ **Using fewer legal resources and staff time**
- ✓ **With greater confidence in legal compliance**

New basis for trust in each other.

Time for some Q & A

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THANK YOU