

Data Sharing Lessons from Alaska

Improving a State's Process for Disclosing Data for Public Health Purposes to Tribal Public Health Organizations

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When a state, territory/freely associated state, or local health agency enters into a data sharing (or data use) agreement for public health purposes with a Tribal-serving organization (TSO) — such as a Tribal Epidemiology Center — there are several considerations to keep in mind even before negotiations begin. The recently completed process used by the Alaska Division of Public Health (DPH), a division within Alaska's Department of Health, and the Alaska Native Tribal Health Consortium (ANTHC) to negotiate a data use agreement demonstrates such considerations.

Below is a summary of the barriers that impeded greater data disclosures from DPH to ANTHC, some of which other jurisdictions may recognize as impeding their disclosures, too. Following are explanations of the approach used to address those barriers, the results of that approach, and the well-considered actions that helped the effort succeed. Other jurisdictions seeking to improve their data sharing/disclosures for public health purposes with Tribal Epidemiology Centers, Tribal public health departments, and other TSOs can use Alaska's approach and legal framework to achieve similarly effective results. See the final section for Lessons Learned during the process.

Barriers to Data Sharing

ANTHC is a non-profit Tribal health organization that provides comprehensive medical services to Alaska Natives and Native Americans in Alaska, who make up approximately 20% of the state's population. The Alaska Native Epidemiology Center (ANEC) is a division within ANTHC. Through ANEC, ANTHC has long sought, and in many cases received, public health data from Alaska DPH to use in its many public health surveillance, education, and intervention efforts. However, from ANTHC's perspective, obtaining requested data was typically a lengthy process where no consistent standards appeared to apply to DPH's consideration of ANTHC's data requests. In some cases, ANTHC was told by DPH that requests could not be fulfilled because applicable laws did not permit such disclosures. On occasion, ANTHC was asked to sign research agreements in response to a data request, which reflected a lack of understanding on DPH's part of ANTHC's public health authorities and responsibilities under federal law.

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For its part, and despite DPH leadership's desire to disclose more public health data to ANTHC, their efforts to do so were often hindered by the lack of a formal data disclosure policy; without one, there were no consistent or recognized standards for evaluating data requests from ANTHC and no process for handling them swiftly, consistently, and effectively. More legal support was needed to fully unravel the issues, some unique to ANTHC's federal public health authority, to ensure that data that was legally permissible to disclose was not being withheld due to unwarranted (but understandable) fears of violating data privacy laws on the part of staff.

Further, the parties were often renegotiating previously agreed-upon general terms for each new data request. As a result, DPH was not maximizing its support of ANTHC's public health efforts in Alaska Native communities — efforts that ultimately improve the health of all Alaska's residents. DPH sought and received funding from ASTHO to hire a legal consultant who could provide dedicated focus to lead its effort to improve its data sharing with ANTHC for the long term.

The Process

Information Gathering

Kick-off meetings with both DPH and ANTHC introduced the consultant leading the project to explain the neutral role she would play in all efforts, including when drafting the legal framework documents, and to invite input on the project's process, goals, and timeline. Information was solicited from key DPH and ANTHC/ANEC leadership and staff on their organization's goals for the data sharing project and priority terms for the data use agreement. They each also shared what they considered to be the barriers to improved data sharing.

Legal Review and Research

The consultant reviewed existing legal agreements permitting DPH's data disclosures to ANTHC to identify previously agreed-upon terms (i.e., a starting point for the new data use agreement). The consultant conducted legal research to confirm DPH's legal authority to disclose health data to ANTHC/ANEC and ANTHC/ANEC's legal authority to have such health data, including Protected Health Information (PHI). Alaska state laws governing the disclosure of data held in certain health data registries/data bases (e.g., vital records, BRFSS, cancer registry) were also researched. The research results were presented in a legal memo to the attorneys for DPH and ANTHC for their review. Embedded in the memo was a user-friendly chart on the referenced state laws, which briefly summarizes to whom and for what purpose each data system's data may be disclosed. The consultant led a joint discussion with the attorneys to determine if they agreed with the memo's legal analysis regarding the applicable laws. They did, which resolved many of the prior barriers to the organizations' efforts to share data.

Suite of Legal Documents

A suite of three documents streamlined the processes of data requests, data request review, and documentation in a legal agreement of any subsequent disclosures. The parties reviewed the consultant-created drafts, negotiated edits and additions to the drafts, and approved final version

- An **Umbrella Agreement** (data use agreement) is the overarching agreement between DPH and ANTHC, negotiated and executed once, that covers the terms universal to all DPH data disclosures to ANTHC for public health purposes. It includes recitations of the legal authorities presented in the legal memo, standard terms found in data use agreements, and other contract terms the parties agreed to during the process. To maintain a neutral role during the drafting of the Umbrella Agreement (and the other documents), the consultant kept a list of issues as yet unresolved among the parties. Once the parties negotiated those issues, any resulting terms were then added to the final version.
- The **Data Disclosure Appendix (DDA)** incorporates by reference the Umbrella DUA. An appendix will be negotiated and executed for each data system from which ANTHC requests data and will cover data disclosure terms specific to that data system and any related legal restrictions. DPH counsel uses the DDA template to create a draft appendix, which is then negotiated and executed by both parties, and ultimately saved and recorded with all other DDAs as appendices of the Umbrella DUA.
- The **Data Request Form** helped DPH standardize and facilitate its processing of ANTHC's data requests. ANTHC completes the form, which solicits a description of the data requested (including specific data fields), the purpose for which it is being requested, and the frequency of disclosure requested, among other things.

Training Provided

A training for both organizations familiarized staff with the new data sharing legal documents, DPH policy, and procedures, and to inform them on how each would be implemented. The training served equally to foster relationships and trust and to improve communications between DPH and ANTHC staff.

The Result

The result of this project, which was supported by Public Health Infrastructure Grant (PHIG) funds, is a new, practical legal framework for data disclosures, including a fully executed Umbrella Public Health Data Agreement entered into by DPH and ANTHC. DPH has also implemented a new data sharing policy. The legal memo and its user-friendly chart on the referenced state laws provided to DPH's and ANTHC's legal counsel will greatly reduce the amount of DPH's legal counsel's time, a limited resource, needed to research and review the relevant applicable law for each new data request from ANTHC. ANTHC and DPH expect that the new DPH policy and legal framework, along with the improved relationship between the organizations, will lead to increased public health data disclosures that will take fewer resources and less time to complete, an impactful result in itself.

Lessons Learned

Below are elements of the approach used in the Alaska project that led to the project's successful outcomes. They can be applied to inform other jurisdictions' efforts to disclose data for public health purposes to Tribal Epidemiology Centers, Tribal public health departments, and other TSOs.

1. It all starts with trust. The history of federal and state governmental agencies betraying trust placed in them by Tribes is long remembered. That history may be a factor, spoken or not, impacting the relationship between a State and a Tribe or TSO and any data sharing negotiations. Come to the table with open hands and keep in mind the saying that change (and relationship building) moves at the speed of trust. And recognize that relationships rarely develop in a straight line; they are a continually evolving understanding of another's experience.
2. To reduce the time needed once negotiations have begun, read up beforehand on the legal authority Tribes and Tribal Epidemiology Centers (TECs) have as public health authorities. Tribes have inherent public health authority as sovereign nations, and TECs have been granted public health powers by federal law. Both are recognized as public health authorities under HIPAA, thus allowing health data, including PHI, to be disclosed to them for public health purposes without need for an individual's express authorization. (See [Barriers and Opportunities for Tribal Access to Public Health Data to Advance Health Equity | Journal of Law, Medicine & Ethics | Cambridge Core](#))
3. Each party has data-sharing priorities and outcomes they hope to achieve with a data use agreement. Each may also identify barriers that have hindered or continue to hinder data sharing. Before any negotiations toward an agreement begin, encourage each party to state those priorities, outcomes, and identified barriers. That will better focus the discussion and later negotiations and will engender in each party the feeling that their concerns and priorities have been heard. Also, the relationship and negotiations will better weather later disagreements if each party communicates an understanding of and respect for the other party's concerns.
4. Yes, be mindful of the risks of sharing health data but also recognize the risks of not sharing. Lawyers are trained to reduce the risk of exposure to liability for their clients. In the context of negotiating data sharing agreements, that often translates to advising clients to share less health data than the law permits. However, in the context of sharing health data for public health purposes, there is also risk associated with not sharing data. Lost opportunities to use data to target public health interventions and get ahead of developing trends increase the risk of worse public health outcomes, including avoidable deaths.
5. Each entity's stock legal agreements are drafted to be self-advantageous. Using one as the starting basis for negotiating a data use agreement with a Tribe or TSO can create imbalance that will work against efforts to openly negotiate all terms of the agreement. Think creatively about how to avoid that imbalance.

6. Particularly where there is a history of failed negotiations or a desire but an inability to get beyond barriers to data sharing to benefit public health efforts, consider involving a neutral party to lead and manage the effort to improve data sharing. Consider contracting with a legal consultant, requesting technical or peer-to-peer assistance, or bringing in someone with “fresh eyes.” The key will be to remain neutral throughout the process. Outside support of someone with legal and project management expertise may provide the legal knowledge a jurisdiction’s counsel may not have – or have time to develop – on the federal and state law issues involved in disclosing PHI to a Tribe or Tribal Epidemiology Center.