

This document contains a sample template for a data sharing agreement and use and disclosure of client information. Within the data sharing agreement there are important areas to consider for inclusion. At a minimum the agreement should specify the following: parties involved, including contact information; the purpose or need for the data sharing agreement; nature of the data to be collected; access and confidentiality of data; how the data is to be used; how and in what situations the agreement can be severed by either party; and relevant legal authorities (tribal, state, national).

DATA SHARING AGREEMENT

between
<Organization Title>
and
<Organization Title>

I. ENTITIES RECEIVING AND PROVIDING DATA

ENTITY RECEIVING DATA:

OFFICE:

CONTACT PERSON:

TITLE:

ADDRESS:

PHONE NUMBER:

EMAIL:

FAX NUMBER:

ENTITY PROVIDING DATA:

CONTACT PERSON:

TITLE:

ADDRESS:

PHONE NUMBER:

EMAIL:

FAX NUMBER:

II. PURPOSE, AUTHORITY AND TERM OF AGREEMENT

A. PURPOSE

To facilitate the health of Indian tribes and Individual American Indians and Alaska Natives X and Y are entering into an agreement which will allow the exchange of data and clarification of data access and utilization. Y will provide data collected to X for the purposes of <specify >.

B. LEGAL AUTHORITY

1. X is an Indian Organization/Tribal Epidemiology Center as defined by federal law ... whose mission is ...
2. Y is a State Health Department whose mission is ... for public benefit.

C. **PERIOD OF PERFORMANCE**

This Agreement shall be effective when signed by both parties and shall continue until terminated pursuant to the termination clause contained herein.

III **DESCRIPTION OF DATA/DATA WORKPLAN**

The following data will be provided under this agreement: <list of specific data items and agreement parameters>

All data generated by this project shall be approved for dissemination by the <specific IRB> Institutional Review Board and <any other relevant approvals, including tribal government>.

IV. **ACCESS TO DATA**

A. **METHOD OF ACCESS AND TRANSFER**

Data will be obtained in the following manner:

B. **PERSONS HAVING ACCESS TO DATA**

All persons who will have access to data must complete a data privacy training through < specify >.

Prior to the transfer of any data, staff members and researchers who will have access to the data shall sign the Use and Disclosure of Client Information, (signed copies shall be provided to X).

C. **FREQUENCY OF DATA EXCHANGE**

Data will be exchanged as needed to meet reporting requirements as well as on an ongoing basis between X and Y staff for the entire length of the project.

V. **SECURITY OF DATA**

X will not attempt to identify individuals' records by any method. Datasets containing protected health information (PHI) shall be encrypted. All reasonable precautions shall be taken to secure the data from individuals who do not specifically have authorized access. Data shall be kept on a password-protected file server located in a secure environment. Project data will be kept in a separate directory on the server which is also password-protected and will be accessible only by X evaluators or staff members specifically authorized access as provided in this Agreement.

VI. **CONFIDENTIALITY**

A. **REGULATIONS COVERING CONFIDENTIALITY OF DATA**

The use and disclosure of information obtained under this contract shall be subject to 42 CFR Subpart 476. X and Y shall maintain the confidentiality of any information which may, in any manner, identify individual subjects.

As this project is specific to AI/AN, all data collected will have the potential to identify AI/AN < tribes, elders, adults, youth, children, etc>. Confidentiality of all data therefore must be ensured.

B. NON-DISCLOSURE OF DATA

X and Y shall not disclose, in whole or in part, the data described in this agreement to any individual or agency not specifically authorized by this agreement.

Data shall be provided on a timely basis. X and Y will document uses and users of the data and will report this information routinely back to the X Principal Investigator.

- C. X and Y will not disclose directly to, or use for the benefit of, any third party confidential information, knowledge or data acquired by virtue of its relationship with the other party named in this Agreement, without the prior written approval of the other party. It is understood and agreed by the parties that the obligations of this paragraph shall survive the expiration or termination of this Agreement.

VII. PAYMENT

< Specify here or reference a separate contract >

VIII. PROPERTY RIGHTS

Original materials prepared by X, including, without limitation: reports, proposals, analysis, writings, sound recordings, pictorial reproductions or materials of any type whatsoever, are and shall remain the <sole and exclusive or joint property> of <stipulate Tribe, organization, or researcher>. X/Y will assert no right, claim or interest of any nature whatsoever with respect thereto, including specifically but, without limitation, any claim to statutory copyright or patent.

Data Use and Ownership

X may request data use approval from Y for development of papers or reports. Such papers or reports must have the specific written approval of the <specific IRB> IRB and <relevant tribal organizations> before such products are submitted for presentation or publication.

Y shall be cited as the source of the data in all tables, reports, presentations, and scientific papers, and X shall be cited as the source of interpretations, calculations, and/or manipulations of the data.

At least forty five (45) days prior to submission or presentation at a meeting/conference, X will furnish a copy of a proposed publication or presentation to the IRB and <relevant

tribal organizations> for review and comment. <Tribal Organization> will have thirty (30) days after receipt of the proposed materials to request that X remove confidential or sensitive information from the materials or rewrite the materials to protect confidential information from disclosure. X may use, reuse and analyze, for teaching and research purposes, the data and findings as reviewed by and approved by <Tribal Organization>.

IX. SEVERABILITY

If any provision of this Agreement or any provision of any document incorporated by reference shall be held invalid, such invalidity shall not affect the other provisions of this Agreement which can be given effect without the invalid provision, if such remainder conforms to the requirement of applicable law and the fundamental purpose of this agreement, and to this end the provisions of this Agreement are declared to be severable.

X. TERMINATION

Either party may terminate this Agreement upon 30 days prior written notification to the other party. If this Agreement is so terminated, the parties shall be liable only for performance rendered or costs incurred in accordance with the terms of this Agreement prior to the effective date of termination.

XI. RIGHT OF INSPECTION

X shall provide Y the right of access to its facilities at all reasonable times, in order to monitor and evaluate performance, compliance, and/or quality assurance under this contract.

XII. ALL WRITINGS CONTAINED HEREIN

This Agreement contains all the terms and conditions agreed upon by the parties. No other understandings, oral or otherwise, regarding the subject matter of this Agreement shall be deemed to exist or to bind any of the parties hereto.

Organization X

Name/Title

Date

Name/Title

Date

Organization Y

Name/Title

Date

Name/Title

Date

USE AND DISCLOSURE OF CLIENT INFORMATION

Staff with access to confidential client information are responsible for understanding rules for use and disclosure of the information. Outlined below are key elements for staff to remember:

A. CONFIDENTIALITY OF CLIENT DATA

1. Individually identifiable client data is confidential and is protected by various state and federal laws.
2. Confidential client information includes all personal information (e.g., name, birth date, social security number, diagnosis, treatment, etc.) which may, in any manner, identify the individual.

B. USE OF CLIENT DATA

1. Client data may be used only for purposes directly described in the data sharing agreement between X, Y, and Z
2. Any personal use of client information is strictly prohibited.
3. Access to data must be limited to those staff whose duties specifically require access to such data in the performance of their assigned duties.

C. DISCLOSURE OF INFORMATION

1. Identified client information may not be disclosed to other individuals or agencies.
2. Questions related to disclosure are to be directed to X.
3. Any disclosure of information contrary to 1 above is unauthorized and is subject to penalties identified in law.

Name (print): _____

Signature: _____

Date: _____

Approved By: _____
Executive Director, Organization X

Signature: _____

Date: _____