



Alaska Division of Public Health

Prevention Promotion Protection

Alaska Section of Epidemiology Summary Data or Limited Data Set Request and Utilization Agreement Form

Please complete the following form to request summary data or a limited data set (LDS) from the Alaska Section of Epidemiology (SOE). Depending on the details of the request, SOE may further aggregate data according to the “Rule of Ones.” See SOE Confidentiality Policies and Procedures and Data Release Protocols, page 14; available at:

https://health.alaska.gov/dph/Epi/Documents/confidentiality/SOE_ConfidentialityPPData.pdf .

Data Request Details

- I. Project Title:**
- II. Short Description/Purpose:**

In the Description, please include...

1. A brief description of the purpose of the analysis and the information being requested;
2. A description of your plan to protect the identifiers from improper use and disclosure;
3. A description of when and how you plan to destroy the identifiers;
4. Whether the project/proposal has been presented to an institutional review board (IRB) and any decisions made by an IRB (attach approved proposal if applicable);
5. Explanation of why this analysis could not practicably be conducted without having access to the requested protected health information; and
6. Proposed outputs for the analyses, e.g., *Epidemiology Bulletin*, journal articles, etc. and an estimated timeframe for the project.

III. Data Requested:

Years or time period of interest:

Disease or condition of interest:

Geographic unit requested:

Specific demographic or other data fields requested:

IV. Personnel Involved with Project:

Name and title of primary person with access to the data:

Agency:

Address:

Phone number:

Fax number:

Person receiving data transfer:

Email address:

Name(s), agencies, and email addresses of other individuals with access to the data or involved with the project:

Utilization Agreement Statement

This agreement ("Agreement") is entered into by the Alaska Section of Epidemiology (SOE), and _____, hereinafter referred to as the Researcher.

The Researcher is engaged in research outlined in the SOE Data Request Form and specifically described as follows: _____

The Researcher agrees and acknowledges that patient confidentiality is of the utmost importance in the use of the Data and in the manner in which all research results are presented and/or published. "Ownership" of the data file remains with the SOE. Under HIPAA, the patient is the "owner" of his/her data; all others have limited rights of use. Accordingly, in consideration of his/her receipt of the Data from SOE, the Researcher agrees as follows:

1. The Researcher agrees to treat the Data received from SOE as private, non-public health information. The Data will never be used as a basis for legal, administrative or other adverse actions that can directly affect any individual about whom personal and/or medical information is included in the Data. All prevailing laws and regulations relating to the protection of patient-identifiable information will be followed (this includes HIPAA privacy regulations).

2. The Researcher understands and agrees that any and all Data which may lead to the identity of any patient, research subject, physician, other person, or reporting facility is strictly privileged and confidential and agrees to keep all Data strictly confidential at all times. Access to the data file will be protected by a password-protected security system.
3. The Researcher agrees that all data exchanged under the provisions of this Agreement may only be used for the purpose specified in the Data Request Form. Acceptable purposes for data use include public health research, public health program evaluation, or public health planning purposes. Any other or additional use of the data may result in immediate termination of the Agreement by SOE.
4. The Researcher agrees to notify SOE in writing within forty-eight (48) hours of his/her becoming aware of any violation of this Agreement, including full details of the violation and corrective action to be taken by the Researcher. The Researcher understands that failure to report violations of the Agreement may result in civil or criminal penalties and termination of access to current and future Data.
5. The Researcher agrees that all data exchanged under the provisions of this Agreement shall remain the sole property of SOE and may not be copied or reproduced in any form or manner. The Researcher agrees to destroy the Data at the end of this project or upon termination of this Agreement.
6. The Researcher agrees that any and all reports or analysis of the Data prepared by the Researcher shall contain only aggregate data. The Researcher further agrees that at no time will he/she determine the identity of any individual or publish any identifying information or information which could lead to the identification of any Data subject. The Researcher agrees not to contact any individuals.
7. To the fullest extent permitted by law, the Researcher shall indemnify, defend, and hold harmless the SOE and its administrators, officers, officials, agents, employees, volunteers, and servants from any and all claims or actions for injuries or damages sustained by any person or property arising directly from the Researcher's conduct under this Agreement. It is specifically agreed between the parties executing this agreement that it is not intended by any of the provisions of this agreement to create in the public or any member thereof a third-party benefit thereunder, or to authorize anyone not a party to this Agreement to maintain a suit for personal injuries or property damage pursuant to the terms of provisions of this Agreement.
8. The Researcher will not discuss in any manner, with any unauthorized person, information that would lead to identification of individuals described in the Data furnished by SOE. Also, Researcher will not provide to any unauthorized person any computer password or file access that protects the Data. Should Researcher become aware of any unauthorized access or disclosure of the Data to other persons, the Researcher will report it immediately to SOE.
9. The Researcher will allow the SOE a pre-publication review of conclusions based upon data. This is to ensure correct interpretation of the contents of the database and to ensure that privacy of the subjects of the Data is maintained. If disagreement exists, the recipient will allow the SOE the opportunity to include comment within the published document. Acknowledgement is to be given to the SOE as the source of data in any publications, articles or studies that are

prepared or published. Publications include peer-reviewed articles, but also any other informal communication (i.e., newsletter) in which portions of the Data may be described. In no event, however, shall Researcher publish identifiable case information without the written consent of SOE.

10. If a longer-term project, the Researcher shall submit to SOE an annual report regarding the progress of the Research Project, all publications resulting from the Research Project, changes in the Research Project protocol or personnel, and any other information requested by SOE.
11. Either party may terminate this Agreement for cause or without cause:
 - a) For Cause: SOE may terminate this Agreement upon breach by Researcher of any material provision of the Agreement.
 - b) Without Cause: Either party may terminate this Agreement without cause by giving the other party at least thirty (30) days' advance written notice thereof.
12. The terms of this Agreement shall be binding upon Researcher, his/her agents, assistants and employees.
13. Agreement Period: This agreement begins upon the date it is fully executed and ends upon completion of the work outlined in the Research Proposal or upon termination of the Agreement by either of the parties.

This Agreement shall be governed by and interpreted under the laws of the State of Alaska. I have read and agree to the above conditions of use for data from the Alaska Section of Epidemiology. By signing, I also agree to observe HIPAA and state of Alaska privacy and confidentiality rules and regulations.

Signature: _____ **Date Requested:** _____

(Print name): _____

Accepted (Program Manager): _____ **Date Approved:** _____

Accepted (Section Chief): _____ **Date Approved:** _____

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<https://health.alaska.gov/dph/Epi/Pages/default.aspx>