**Alaska Department of Health, Division of Public Health,
Health Analytics and Vital Records Section**

# Vital Records Research Application

## Introduction

### Confidentiality of Vital Records

Alaska vital records contain protected health information (PHI) and are confidential under [Alaska Statute (AS) 18.50](https://www.akleg.gov/basis/statutes.asp#18.50). Birth records are confidential for 100 years after the date of birth and all other vital records are confidential for 50 years after the date of the event. Vital records data may be disclosed for certain purposes such as research, public health, or health care operations with approval from the Alaska Health Analytics and Vital Records Section (HAVRS). This includes data on births, deaths, fetal deaths, linked birth-infant deaths, marriages and divorces collected under the state’s Electronic Vital Records System (EVRS) as well as inpatient and outpatient health facility discharge data collected under the Health Facilities Data Reporting (HFDR) program. Requests for individual-level data with or without personally identifying information (PII) or for non-public aggregate-level data with or without cell size suppression must undergo review.

HAVRS is a covered entity under the Health Insurance Portability and Accountability Act and must abide by the Standards for Privacy of Individual and Identifiable Health Information, Final Rule (Privacy Rule) [[45 CFR § 160, 162, and 164](https://www.hhs.gov/hipaa/for-professionals/privacy/index.html)]. If access to confidential information is requested, individual-level data linkages are planned, or contact with subjects is intended, data requests must be consistent with both state and federal law governing use and disclosure of data and will only be approved when safeguards ensuring the privacy of individuals are in place and thoroughly guaranteed. Requestors may not obtain access to any more information than is [minimally necessary](https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/minimum-necessary-requirement/index.html).

Certain vital records (such as records of adoption and induced terminations) are further restricted by state law and additional data are not available. Requests for certified copies of vital records for personal or legal use should be directed to the HAVRS Issuance Unit: BVSOffice@alaska.gov.

### Application Process

Health care facilities who participate in the HFDR program are eligible to purchase inpatient and outpatient limited data sets for health care operations (HCO) purposes. Please refer to the [HFDR Program Guidelines](https://health.alaska.gov/dph/VitalStats/Pages/HFDR/default.aspx) or contact HealthAnalytics@alaska.gov for more information on applying for HCO data sets.

Users requesting access to vital records data for research or public health purposes must fully complete this application form and include any supporting documentation requested. Research teams or organizations should select a single principal investigator to act as the point of contact for their application and submit only one application per project regardless of the number of co-investigators. Applications should be detailed enough to allow HAVRS staff to fully evaluate the proposed project and the intended data use. Failure to fully complete an application may result in the rejection of your request or delays in processing. HAVRS staff are available to answer any questions you have during the application process.

E-mail completed forms to HealthAnalytics@alaska.gov, or fax to (907) 465-4689, or mail to Health Analytics and Vital Records, Research Unit | PO Box 110675 | Juneau, AK 99811.

### Review Process

Access to confidential vital records data must receive approval through a formal review process. The review process is designed to ensure that vital records, entrusted to HAVRS by the Alaska public and legislature, will only be available to qualified and authorized personnel undertaking approved research or public health uses, and that the confidentiality of subjects will be strictly maintained. The review process begins with the principal investigator completing this research application. After the completed application is submitted, HAVRS staff will review and evaluate the application and consider factors such as: the applicant’s qualifications and experience; the project’s purpose and objective; proposed data use; potential for reducing morbidity and mortality, contributing to the health of newborns and mothers, or improving health disparities in vulnerable populations; provisions for maintaining confidentiality; technical feasibility; and staff capacity.

Please allow up to six weeks for review. Once HAVRS has approved an application the principal investigator and all other personnel with access to the data will be required to sign a Data Use Agreement. This agreement establishes guidelines for the release of data and includes descriptions of the data being shared, the approved limited uses of these data, the terms and conditions under which data are provided, as well as confidentiality and data security provisions. Rejected applications may be re-submitted with revisions.

### Renewal of Authorization

HAVRS requires annual renewal of authorization for ongoing access to confidential vital records data unless a longer term is discussed and approved beforehand (no more than 5 years). Requests for renewal must specify any changes in the project or personnel who will have access to the data. Vital records data must be returned to HAVRS or destroyed upon completion of the project or termination of authorization, whichever occurs first.

### Data Fees

Charges for computer time, programming time, and any other staff time involved in fulfilling data requests are billed at $75 per hour. Charges for projects taking less than one hour per year or from student researchers may be waived or discounted at the discretion of the HAVRS Research Unit.

There are additional per item charges for non-certified (white) copies of vital records ($10 per item), or for linkages of a researcher-supplied individual-level data set to a vital records data set ($2.50 per match).

Recurring requests for non-discharge vital records data provided at regular intervals (e.g. monthly or quarterly updates) may require an annual data maintenance fee of $1,500 per year.

Recurring or ad hoc requests for individual-level inpatient or outpatient discharge data are billed at $500 per discharge date quarter (plus $75 per file distribution) or $2,000 per discharge date year (no file distribution fee).

## Applicant Information

Project Title: Click or tap here to enter text.

Application Date: Click or tap to enter a date.

**Principal Applicant:** This person is designated as the principal point of contact for this project and application. Attach a resume and/or CV.

Name and Title: Click or tap here to enter text.

Affiliation: Click or tap here to enter text.

E-Mail: Click or tap here to enter text.

Phone: Click or tap here to enter text.

**Other Applicants:** Include all other personnel who, for any reason, will have access to the data. Attach a resume and/or CV for each person (student investigators must include their primary mentor or advisor).

Name and Title: Click or tap here to enter text.

Affiliation: Click or tap here to enter text.

E-Mail: Click or tap here to enter text.

Phone: Click or tap here to enter text.

Name and Title: Click or tap here to enter text.

Affiliation: Click or tap here to enter text.

E-Mail: Click or tap here to enter text.

Phone: Click or tap here to enter text.

*(Add additional personnel and pages as needed)*

*Applicants are required to sign a Data Use Agreement form prior to the release of confidential data. Personnel added after application must add their signatures to the Data Use Agreement.*

## Project Information

1. Please review these resources before submitting a request to ensure the data you need is not already available. Otherwise explain why this project cannot be completed using existing data sources.
	1. [HAVRS Annual Reports, Data Dashboards, Special Reports/Tables](https://health.alaska.gov/dph/VitalStats/Pages/data/default.aspx)
	2. [CDC WONDER](https://wonder.cdc.gov/) Online Vital Records Databases
	3. [CDC Vital Records Public Use Data Files](https://www.cdc.gov/nchs/data_access/vitalstatsonline.htm)
	4. [HCUP State Inpatient/Emergency Department Database](https://www.hcup-us.ahrq.gov/databases.jsp)

Click or tap here to enter text.

1. Provide a description of the proposed research project and explain how the data requested will be used. Please include information such as: the project’s objective; hypotheses to be tested; research questions you intend to answer; the methodological and statistical techniques to be employed; demographic or geographic populations of interest; and any other relevant project information that will assist HAVRS in evaluating your proposal. Projects without a clear and well-defined limited data use may result in rejection or delays in processing.

Click or tap here to enter text.

1. Describe the public health significance of your project and explain how it will contribute to the reduction of morbidity and mortality, contribute to the health of newborns and mothers, or improve health disparities in vulnerable populations.

Click or tap here to enter text.

1. Describe your plans for the release of results related to this project, including private or public dissemination (e.g. publications, presentations, searchable databases, etc.).

Click or tap here to enter text.

1. Do you agree to allow HAVRS to review project results derived from our data (publications, presentations, tables, figures, etc.) at least two weeks prior to dissemination?

[ ] Yes [ ] No

1. Unless an exemption is explicitly approved by HAVRS, do you agree to abide by all of the following data suppression rules?
	1. No figure or cell (including totals) with <6 observations will be reported.
	2. Rates or other calculations based on <6 observations will not be reported.
	3. Rates or other calculations based on <20 observations will be noted as statistically unreliable.
	4. Geographic units with <1,000 residents will not be reported.

[ ] Yes [ ] No

1. When do you expect to complete the proposed project?

Click or tap here to enter text.

1. Do you agree to submit periodic requests for renewal of authorization for projects that require ongoing access to HAVRS data, and to return or destroy the data provided after completion of the project or termination of authorization?

[ ] Yes [ ] No

1. Are you requesting data with personally identifiable information (e.g. direct identifiers such as: certificate numbers, names, addresses, event dates, social security numbers, etc.)?

[ ] Yes [ ] No

* 1. If yes, explain the need for identification and describe how that information will be used.

Click or tap here to enter text.

1. Do you intend to use non-identifiable information in the data to determine the identity of any subjects or individuals in the data (e.g. combinations of indirect identifiers such as sex, race, age, birth place, etc.)?

[ ] Yes [ ] No

* 1. If yes, explain the need for identification and describe how that information will be used.

Click or tap here to enter text.

1. Will contact be made with any subjects or other individuals identified using the data?

[ ] Yes [ ] No

* 1. If yes, explain the need for contact and describe how subjects will be reached. Attach documentation such as contact protocols, letters, scripts etc. to your application.

Click or tap here to enter text.

* 1. If yes, will subjects be asked to provide their informed consent to participate in your project and permission for the release and/or use of data pertaining to them?

[ ] Yes [ ] No

* + 1. If yes, include a copy of informed consent form with your application. If no, explain why informed consent will not be sought.

Click or tap here to enter text.

1. Has this project been reviewed by an accredited Institutional Review Board (IRB) or Human Investigations Committee (HIC)?

[ ] Yes [ ] No

1. If yes, provide the name of the institution/committee, the decision reached, and the date of the review. Attach copies of IRB/HIC documentation to this application.

Click or tap here to enter text.

1. If no, describe why IRB/HIC review was not sought.

Click or tap here to enter text.

1. Describe each of the following safeguards in place for ensuring that data containing protected health information will not be copied or re-disclosed, and access will be limited only to authorized individuals.
	1. Administrative (i.e. formal policies and procedures we have in place to protect PHI).

Click or tap here to enter text.

* 1. Technical (i.e. how we use technology and encryption to protect PHI).

Click or tap here to enter text.

* 1. Physical (i.e. how we protect our physical infrastructure, including buildings and equipment).

Click or tap here to enter text.

1. Describe any additional primary or secondary data sources that will be used in your project.

Click or tap here to enter text.

1. Is there any other information you would like to provide that will help us evaluate your project or process your application (e.g. project deadlines, file format preferences, etc.)?

Click or tap here to enter text.

## Data Description

Data requests must be limited strictly to the [minimum necessary](https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/minimum-necessary-requirement/index.html) amount of information required. Be prepared to provide detailed justifications for all events, records, fields, and field values requested and describe exactly how each data element will be used.

1. What event(s) are you requesting data for? *(Check all that apply)*

|  |  |
| --- | --- |
| **Vital Records (1970-Present)** | **Hospital Discharges (2015-Present)** |
| [ ]  Birth | [ ]  Inpatient Hospitalization |
| [ ]  Death | [ ]  Outpatient Emergency Dept.  |
| [ ]  Fetal Death | [ ]  Outpatient Non-Emergency Dept. |
| [ ]  Linked Birth-Infant Death |  ([ ]  Incl. Ambulatory Surgery Centers) |
| [ ]  Marriage |  |
| [ ]  Divorce |  |

Other: Click or tap here to enter text.

1. What level of detail are you requesting data in? *(Check all that apply)*

[ ]  Aggregate-level data (i.e. each data point represents a summary of individual-level records)

[ ]  Individual-level data (i.e. each data point represents an individual event record)

1. Specify timeframe of interest.

Click or tap here to enter text.

1. Specify geographic unit of interest. *(Check the lowest geographic unit requested)*

[ ]  Statewide

[ ]  Public Health Region

[ ]  Borough/Census Area

[ ]  Community

[ ]  Other: Click or tap here to enter text.

1. Specify location of geographic unit of interest. *(Check all that apply)*

[ ]  Place of residence (includes Alaska resident data, regardless of place of event)

[ ]  Place of occurrence (includes Alaska event data, regardless of place of residence)

[ ]  Other: Click or tap here to enter text.

1. Specify demographic unit(s) of interest. *(Check all that apply)*

[ ]  Sex ([ ]  Male; [ ]  Female)

[ ]  Age ([ ]  10-year groups; [ ]  5-year groups; [ ]  Other: Click or tap here to enter text.)

[ ]  Race ([ ]  White; [ ]  Black; [ ]  American Indian/AK Native; [ ]  Asian/Pacific Islander)

[ ]  Ethnicity ([ ]  Hispanic; [ ]  Non-Hispanic)

[ ]  Other: Click or tap here to enter text.

1. Will the data be linked to any other data sources?

[ ] Yes [ ] No

* 1. If yes, describe the other data source(s) and specify if the linkage will be performed at an aggregate-level or individual-level.

Click or tap here to enter text.

* 1. If individual-level record linkage will be performed, specify what field(s) will be used to link the datasets and describe the matching method to be used (e.g. deterministic or probabilistic matching, exact or partial matching, etc.).

Click or tap here to enter text.

## Data Elements

Vital records data are collected using the 2003 Revision [U.S. Standard Certificate and Report](https://www.cdc.gov/nchs/nvss/revisions-of-the-us-standard-certificates-and-reports.htm) forms for [Births](https://www.cdc.gov/nchs/data/dvs/birth11-03final-ACC.pdf), [Deaths](https://www.cdc.gov/nchs/data/dvs/DEATH11-03final-ACC.pdf), and [Fetal Deaths](https://www.cdc.gov/nchs/data/dvs/FDEATH11-03finalACC.pdf). Births before 2013 and Deaths/Fetal Deaths before 2014 used the [1989 Revision forms](https://stacks.cdc.gov/view/cdc/11150). Discharge data are collected using the [UB-04 Uniform Billing Claim form](https://www.cdc.gov/wtc/pdfs/policies/ub-40-P.pdf). Please refer to these forms for the data elements available in each event type.

Cause of death and discharge diagnosis information is currently coded using the [International Classification of Diseases Tenth Revision (ICD-10)](https://icd.who.int/browse10/) and [Clinical Modification (ICD-10-CM)](https://icd10cmtool.cdc.gov/) manuals for mortality and discharge data, respectively. Deaths before 1999 and discharges before October 2015 are coded using the [ICD Ninth Revision](https://www.cdc.gov/nchs/icd/icd9.htm) (ICD-9) and [Clinical Modification (ICD-9-CM)](https://www.cdc.gov/nchs/icd/icd9cm.htm) manuals, respectively. Provide ICD codes when requesting specific disease and injury categories. Records can be classified using either a single underlying cause/principal diagnosis code or by scanning multiple contributing cause (up to 19)/secondary diagnosis codes (up to 29). Specify whether case definitions are based on single or multiple ICD code analysis.

1. **If requesting aggregate-level data**: Describe the aggregation requested, inlcuding the event type, row and column variables, cross-tabulations, value groupings, statistics requested, etc. Include a spreadsheet or blank table shell with your application illustrating the desired table layout.

**Example:** *“Aggregate-level summary table of Alaska resident deaths and rates per 100,000 population (if available) grouped by cause (underlying cause = Suicide: U03, X60-X84, Y870) year (individual years from 2015 to 2020), and sex (All values); cross-tabulated by age (columns with 10-year age groups from <20 to 40+). Table shell attached.”*

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| ***Cause*** | ***Year*** | ***Sex*** | ***<20*** ***Years*** | ***20-29 Years*** | ***30-39 Years*** | ***40+******Years*** |
| *Suicide* | *2015* | *Male*  | *N (Rate)* | *…* | *…* | *…* |
| *…* | *…* | *Female* | *…* | *…* | *…* | *…* |
| *…* | *…* | *Unknown* | *…* | *…* | *…* | *…* |
| *…* | *2016* | *Etc.* | *…* | *…* | *…* | *...* |

Click or tap here to enter text.

1. **If requesting individual-level data**: Describe the individual-level data elements(s) requested, including the event type, variable number and name (referring to forms above), and the item values (or re-codes) required. Explain why each element is minimally necessary and describe how that element will be used.

**Note:** Individual-level data requests, particularly those involving direct identifiers or combinations of indirect identifiers that could potentially identify individual cases, may require more extensive review than pre-aggregated data due to the level of detail involved. Access to individual-level data with direct or indirect identifiers may require IRB/HIC approval from an accredited institution and additional departmental approval. Only request individual-level data if your project can not be accomplished using aggregate-level data (e.g. your project requires complex record-level regression analysis, large, multivariate cross-tabulations, or linkage using identifiable information).

**Example:***“Individual-level death data table (2003 Revision U.S. Standard Certificate) Requested elements, values, and justifications attached:”*

|  |  |  |
| --- | --- | --- |
| ***Variable*** | ***Value(s)*** | ***Minimum Necessary Justification/Proposed Use*** |
| *Item 29. Date of Death (YYYY/MM)* | *2015/01 to 2020/12* | *Needed for temporal analysis of suicidality. Will be used to calculate mortality rates, and determine if suicides follow seasonal patterns (regression model specifications and references described in Project Description).* |
| *Item 32. Underlying Cause of Death (Coded)* | *U03, X60-X84, Y870 (Suicides)* | *Needed for analysis of suicide methods by ICD code. Will be used to summarize deaths by method, calculate method-specific mortality rates, and as a control for firearm vs non-firearm suicides in regression analysis.* |
| *Item 2. Sex* | *All Values* | *Needed for analysis of demographic characteristics of decedents. Will be used to summarize deaths by sex, calculate sex-specific mortality rates, and as a control for male vs female suicides in regression analysis.* |
| *Etc.* | *…* | *…* |

Click or tap here to enter text.