Alaska Department of Health, Division of Public Health, Health Analytics and Vital Records Section Data Request Application

I. Introduction

1. Background

The Alaska Health Analytics and Vital Records Section (HAVRS), also known as the Bureau of Vital Statistics (BVS), is responsible for managing access to vital statistics data collected by the Alaska Electronic Vital Records System (EVRS). This includes certificates and reports of birth, death, fetal death, marriage, divorce, adoption, and induced termination. HAVRS is also responsible for managing access to discharge data collected by the Alaska Health Facilities Data Reporting (HFDR) program. This includes billing records collected from inpatient or outpatient hospitals, emergency departments (ED), and ambulatory surgery centers (ACS). If access to HAVRS-managed data is needed, requests must be consistent with both state and federal laws governing use and disclosure of information and will only be approved when safeguards ensuring the privacy of the individuals contained in the data are thoroughly guaranteed.

2. Confidentiality of Data

HAVRS records contain protected health information (PHI) and are confidential under the Alaska Vital Statistics Act [AS 18.50]. Birth records are confidential for 100 years after the date of birth and other records are confidential for 50 years after the date of the event [AS 18.50.310(f)]. Access to records before this time is generally restricted to the individual subject(s) of the record, or to certain family members, legal representatives, and persons who can prove they are legally entitled. Certain records, such as reports of adoption and induced termination, and records related to treatment for substance use disorders may also receive additional confidentiality protections under state and federal laws.

HAVRS may permit the disclosure and use of data contained in confidential vital statistics records, other than reports of induced terminations of pregnancy, for statistical and research purposes provided no identification of any individual can be made from the information furnished [AS 18.50.310(b); 7 AAC 05.950]. HAVRS is a covered entity under the Health Insurance Portability and Accountability Act (HIPAA) and must abide by the Standards for Privacy of Individual and Identifiable Health Information, Final Rule (HIPAA Privacy Rule) [45 CFR 160, 162, and 164]. The HIPAA Privacy Rule permits disclosure and use of PHI for research purposes, public health practice activities, health care operations, and other purposes. Data are not available for commercial purposes. Requestors may not obtain access to any more information than is minimally necessary for the approved purpose [45 CFR 164.502(b), 164.514(d)].

3. Acceptable Uses of Data

a. **Research** refers to a systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge. Qualified researchers may request access to aggregated data and de-identified limited data sets for research purposes. Researchers requesting access to individually identifiable data sets must be reviewed and obtain a waiver of the HIPAA Privacy Rule's individual authorization and/or Common Rule's consent requirements from an accredited Institutional Review Board (IRB) or Human Investigations Committee (HIC).
b. **Public Health Practice (PHP)** refers to the collection and analysis of data by a public health authority to prevent disease or injury and to improve the health of communities through such

activities as disease surveillance, program evaluation, and outbreak investigation. A public health authority is defined as an agency or authority of the United States, a State, a territory, a political subdivision of a State or territory, or an American Indian/Alaska Native tribe, or a person or entity acting under a grant of authority from or contract with such public agency that is responsible for public health matters as part of its official mandate. Qualified public health authorities may request access to aggregated data, de-identified limited data sets, and identifiable data sets for PHP purposes. Public health authorities requesting access to identifiable data sets may be required to have their requests reviewed by the Alaska Division of Public Health Scientific Review Committee (SRC) or by an accredited Institutional Review Board (IRB) or Human Investigations Committee (HIC).

c. **Health Care Operations (HCO)** refers to certain administrative, financial, legal, and quality improvement activities that are necessary for the facility to run its business and to support the core functions of treatment and payment. Alaska facilities that participate in the HFDR program and are in good-standing may request aggregated data and de-identified limited data sets for HCO purposes. Facilities should refer to the HFDR Program Guidelines for more information about requesting discharge limited data sets for HCO purposes. Requests for vital statistics aggregated data or de-identified limited data sets may complete this application.

4. Requesting Access to Data

Those requesting certified copies of vital records for personal and legal use are directed to contact the HAVRS Issuance Unit at BVSOffice@alaska.gov or visit www.vitalrecords.alaska.gov for more information. Those requesting information subject to the Alaska Public Records Act [AS 40.25] or the U.S. Freedom of Information Act (FOIA) are directed to contact the Alaska Department of Health's Public Records Officer at DOH.Public.Records.Req@alaska.gov. Those requesting access to HAVRS data for research, public health practice, or healthcare operations purposes are directed to complete this Data Request Application and Data Use Agreement (DUA) form and submit to the HAVRS Research Unit at HealthAnalytics@alaska.gov. Before applying, please ensure the information you need is not already available from one of the following sources:

a. HAVRS regularly releases comprehensive annual reports on vital statistics, discharges, and induced terminations. Additional data are also periodically made available through online data tables, interactive dashboards, and special reports. These can be found on the HAVRS Data and Statistics website.
b. HAVRS participates in the Centers for Disease Control and Prevention (CDC) National Vital Statistics System (NVSS). The NVSS provides the most complete data on vital statistics in the United States. Resources include the CDC WONDER ad-hoc query system for aggregated data requests, as well as individual-level data sets in the form of public use data files and restricted-use data files for researchers.
c. HAVRS participates in the Agency for Healthcare Research and Quality (AHRQ) Healthcare Cost and Utilization Project (HCUP). HCUP's databases can be used to identify, track, and analyze national trends in healthcare utilization, access, charges, quality, and outcomes. Resources include AHRQ Data Tools and individual-level data sets in the form of the State Inpatient Database, State Emergency Department Database, and Ambulatory Surgery and Services Database for researchers. Contact HCUP-RequestData@ahrq.gov for more information.
d. HAVRS participates in the National Association for Public Health Statistics and Information Systems (NAPHSIS) Electronic Verification of Vital Events (EVVE). EVVE enables state, federal,

local, and tribal governmental agencies or qualified private healthcare, insurance, and benefits agencies to electronically verify when a certificate of birth or death exists in a participating U.S. jurisdiction. This enables administrative agencies to establish proof of age, citizenship and identification for employement purposes, to issue benefits or other documents, to assist in determining eligibility for public programs or benefits, or to establish proof of birth or death for fraud prevention purposes. Contact Systems@naphsis.org for more information.

e. HAVRS participates in the CDC's National Death Index (NDI). NDI enables public health and medical researchers to obtain mortality follow-up information on study participants. The NDI can be used to return to the researcher the date of death, state of death, death certificate number, and cause of death for all matches to a research-supplied patient list. Contact NDI@cdc.org for more information.

5. Application and Review Process

Access to data must receive approval through a formal application and review process. This process is designed to ensure that records, entrusted to HAVRS by the Alaska public and the state legislature, will only be available to qualified and authorized personnel undertaking approved uses, and that the confidentiality of data and the privacy of individuals will be strictly maintained. Users requesting access to data must fully complete this data request application. Research teams and organizations should select a principal investigator (PI) to act as the primary applicant and point of contact for their request and submit only one application per project regardless of the number of co-investigators. Student researchers should include a faculty advisor or mentor on their application. Applications should be detailed enough to allow HAVRS to reasonably evaluate the applicant's qualifications, eligibility, and proposed 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. Questions and completed applications and supporting documentation should be emailed to HealthAnalytics@alaska.gov.

After the completed application is received, HAVRS staff will review and evaluate the application, considering 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 PI and all other personnel with access to the data may be required to sign a Data Use Agreement (DUA) with HAVRS. DUAs 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 requirements. Rejected applications may be re-submitted with corrections or revisions.

HAVRS requires periodic renewal of authorization for ongoing access to confidential data, with authorization not to exceed five (5) years before renewal is required. Requests for renewal must specify any changes in the project or personnel with access to the data. Upon completion of the project or termination of authorization, whichever occurs first, data must be returned to HAVRS or destroyed.

6. Data Fees

Vital Statistics Services (Birth/Death/Fetal Death/Marriage/Divorce Data)	Cost
Special Research/Data Analysis Requests (per staff hour) [a]	$75
Data Sets – More Frequent Than Annual Distributions (access fee + per distribution) [b]	$1,500 + $75
Data Matching (per positive match) [c]	$2.50
Uncertified White Copies (per copy) [d]	$10

Health Facilities Data Reporting Program Services (Inpatient/Outpatient Discharge Data)	Cost
Special Research/Data Analysis Requests (per staff hour) [a]	$75
Data Sets – Quarterly Distributions (per discharge quarter + per distribution) [e]	$500 + $75
Data Sets – Annual Distributions (per discharge year) [e]	$2,000

a. HAVRS is authorized to prescribe fees for services rendered [AS 18.50.330]. Fees may be subject to change without notice. Fees for research, analysis, programming, administrative, and other staff time involved in fulfilling special research/data analysis requests are billed at $75 per hour. Requests from students or non-profits may be waived or discounted at the discretion of HAVRS, pending staff capacity and reporting burden.

b. Requests for data sets distributed at regular intervals more frequently than annually (e.g., quarterly or monthly) require an annual data maintenance fee of $1,500 per year plus $75 per file distribution, in addition to staff hours. You will be provided with the most up to date data on events that occurred during the date ranges specified, available as of the time of the distribution. Note that data are always subject to change due to late registrations, amendments, and corrections. Information may change depending on when the data are distributed. Provisional data may be provided at the discretion of HAVRS.

c. Data matching refers to linking a client supplied data set containing individually identifiable information to a HAVRS data set to create a dataset with elements from both files. Matching requires a first name, last name and date of birth at a minimum, but middle name, maiden name, social security number, sex, and place of birth can help improve match accuracy if available. Matching requests are restricted to public health authorities with an approved data use agreement or researchers who have obtained a waiver of the HIPAA Privacy Rule's individual authorization and/or Common Rule's consent requirements from an accredited IRB or HIC.

d. White copies include the complete long-form vital event certificate, including individually identifiable information and demographic and medical details. White copies are restricted to public health authorities with an approved data use agreement or researchers who have obtained waiver of the HIPAA Privacy Rule's individual authorization and/or Common Rule's consent requirements from an accredited IRB or HIC.

e. Requests for Health Facilities Data Reporting program 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). The most recently available quarterly data releases are provisional and subject to change. Updates to files when final data are available are provided to data purchasers at no additional charge.

II. Applicant Information

Project Title:

Application Date:

Principal Investigator: This person is designated as the principal point of contact for this project and application. Attach a resume or curriculum vitae (CV).

Name and Title:

Affiliation:

E-Mail:

Phone:

Other Applicants: Include all other personnel who, for any reason, will have access to the data (student researchers must include a faculty advisor or mentor).

Name and Title:

Affiliation:

E-Mail:

Phone:

Name and Title:

Affiliation:

E-Mail:

Phone:

(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.

III. Project Information

1. This project is primarily *(select one)*: ☐ Research ☐ Public Health Practice ☐ Healthcare Operations

2. Explain why this project cannot be completed using any of the existing data sources described in Part I.

3. Describe the project and explain how the data will be used.
    - *Note: Researchers should include information such as: research goals; hypotheses; methodology; statistical techniques; populations of interest; etc. Public health authorities should include information such as: surveillance or prevention program goals; statutory authority to receive information; funding or grant sources; target populations; etc.*

4. Describe the public health significance of the project, such as 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.

5. Describe plans for the release of information produced by this project, such as private or public dissemination of publications, presentations, searchable databases, etc.

6. When do you expect to complete the project?

7. Do you agree to allow HAVRS to review project results derived from our data (including publications, presentations, tables, figures, etc.) at least ten (10) regular business days prior to public dissemination?

   ☐Yes ☐No

8. Do you agree to follow HAVRS data suppression requirements, including the following?
   a. No figure or cell (including totals) with less than six (<6) observations will be reported.
   b. Rates or other calculations based on less than six (<6) observations will not be reported.
   c. Rates or other calculations based on less than twenty (<20) observations will be noted as statistically unreliable.
   d. Geographic units with less than twenty thousand (<20,000) population will not be reported.

   ☐Yes ☐No

9. 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

10. Does your project require personally identifiable information (e.g., direct identifiers such as: certificate numbers, subject names, residence street addresses, social security numbers, etc.)?

    ☐Yes ☐No

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

11. 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, birthplace, etc.)?

    ☐Yes ☐No

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

12. Does your project involve contact with any living subjects or other individuals identified in the data?

☐Yes ☐No

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

b. 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

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

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

☐Yes ☐No

a. 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.

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

14. Describe this project's safeguards for ensuring that information will not be used inappropriately, re-disclosed, and access will be limited only to authorized individuals.

    a. Administrative (i.e., formal policies and procedures we have in place to protect PHI).

    b. Technical (i.e., how we use technology and encryption to protect PHI).

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

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

16. 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.)?

IV. Data Description

Data requests must be limited strictly to the minimum necessary amount of information required. Be prepared to provide detailed justifications for all events, records, variables, and variable values requested and to 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)	HFDR Discharges (2016—Present)
☐ Birth	☐ Hospitalization
☐ Death (☐Linked Infant Death-Birth)	☐ Emergency Department
☐ Fetal Death	☐ Other Outpatient (Non-ED & Surgery)
☐ Marriage	
☐ Divorce	

Other:

2. Specify date range(s) of interest.

3. Specify geographic unit of interest. *(Check the smallest unit that applies)*

☐ State-level
☐ Public Health Region-level
☐ Borough/Census Area-level (county equivalent)
☐ Community-level
☐ Other (specify):

4. Specify place of interest for the unit above. *(Check all that apply)*

☐ Place of residence (i.e., where the subject resided, regardless of where the event occurred)
☐ Place of occurrence (i.e., where the event occurred, regardless of where the subject resided)
☐ Other (specify):

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

☐ Gender: ☐Male ☐Female
☐ Age: ☐10-year groups ☐5-year groups ☐Single-years
☐ Race: ☐White ☐Black ☐American Indian/Alaska Native ☐Asian ☐Hawaiian/Pacific Islander
☐ Ethnicity: ☐Hispanic ☐Non-Hispanic
☐ Other (specify):

6. Specify causes (for death data) or diagnoses (for discharge data) of interest.
   - *Note: Deaths are classified using International Classification of Diseases (ICD) codes (ICD-9 before 1999; ICD-10 after). Discharges are classified using ICD Clinical Modification (CM) codes (ICD-9-CM before 2016; ICD-10-CM after). Please provide specific codes. Records will be queried by the underlying cause (for death data) or principal diagnosis (for discharge data) unless inclusion of multiple contributing causes (for death data) or secondary diagnoses (for discharge data) is specified.*

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

☐Yes ☐No

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

   b. 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.).

8. What level of record detail are you requesting? *(Check all that apply)*

☐ Aggregate-level (macro) data (i.e., each data point represents a summary of individual records)
☐ Individual-level (micro) data (i.e., each data point represents an individual record)

a. If aggregate-level, describe the table layout requested, including variable(s) to group or cross-tabulate results by and measures (such as counts or rates) requested. Include a blank table shell illustrating the desired layout(s) with your application.

b. If individual-level, list the variables required for each event type and explain why each variable and variable value is necessary. Specify if any variable values should be filtered out or recoded. Note: Individual-level data requests, including limited data sets and identifiable data sets, may require more extensive review and Department-level approval compared to aggregate-level data sets due to the increased level of detail provided. Only request individual-level data if your project can not be accomplished using aggregate-level data (e.g., aggregation would involve complex multi-variate grouping and cross-tabulation; analysis involves complex multi-variate regression, etc.).

- Note: Vital records data are collected based on fields from the 2003 Revision U.S. Standard Certificate and Report forms for births, deaths, and fetal deaths. Births before 2013 and deaths/fetal deaths before 2014 are based on fields used in the 1989 Revision forms. Discharge data are collected based on fields from the UB-04 Uniform Billing Claim form. Please refer to these forms for the variables and variable values available for each event type.

Aggregate-level data example:
Group Variables: Year, Sex
Crosstabulation Variable: Age Group
Measure: Events

Year	Sex	<65 Years	65+ Years
2020	Female	1	1
	Male	2	1
2021	Female	1	0
	Male	3	1

Individual-level data example:
Variables: Observation, Year, Sex, Age Group

Observation	Year	Sex	Age Group
1	2020	Female	<65
2	2020	Female	65+
3	2020	Male	<65
4	2020	Male	65+
5	2020	Male	<65
6	2021	Female	<65
7	2021	Male	<65
8	2021	Male	<65
9	2021	Male	65+
10	2021	Male	<65

Alaska Department of Health, Division of Public Health, Health Analytics and Vital Records Section Data Use Agreement

I. Purpose

The purpose of this Data Use Agreement (DUA) is to establish guidelines for the use and disclosure of confidential data owned and managed by the Alaska Department of Health, Division of Public Health, Health Analytics and Vital Records Section, also known as the Bureau of Vital Statistics, and hereafter referred to as HAVRS, to the Recipient:

II. Authority

HAVRS is responsible for administration of the State of Alaska's system of vital statistics as established under Alaska Statute Title 18, Chapter 50: Vital Statistics Act [AS 18.50]. Section 310: Disclosure of Records [AS 18.50.310] authorizes HAVRS to permit use and disclosure of data contained in vital statistics records, other than reports of induced terminations of pregnancy, for research purposes. The Standards for Privacy of Individually Identifiable Health Information (Privacy Rule), promulgated under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) [45 CFR 160, 162, and 164] authorizes HAVRS to permit use and disclosure of data for research, public health practice activities, healthcare operations and other purposes.

III. Data Elements

IV. Approved Use

V. Terms and Conditions

Any use of data for purposes other than approved are not authorized and violate this DUA. Violations will result in termination of access to the data and prohibit future releases of data. The Recipient agrees to provide the following assurances with respect to the data:

1. Data Confidentiality and Non-Disclosure Requirements

- I acknowledge that the data are confidential and may contain protected health information as defined by state and federal law.
- I will not use, nor permit others to use, the data other than as described in the approved use without approval of HAVRS.
- I will not use, nor permit others to use, the data to learn the identity of any person or establishment included in the data without approval from HAVRS.
- I will not link, nor permit others to link, the data with individually identifiable information from other sources without approval of HAVRS.
- I will not disclose, nor permit others to disclose, the data to anyone who has not signed this DUA without approval of HAVRS.
- If it is not technically feasible for all users with access to the data to sign this DUA, the primary applicant will be responsible for ensuring other users (e.g., staff, business associates, contractors, or other agents) are familiarized with and agree to abide by this DUA.

2. Data Dissemination and Reporting Requirements

- Data may only be publicly disseminated in aggregated or de-identified form, subject to approval of HAVRS.
- If provisional data are provided, those data will include a statistical note. Recommended note: *Data from <date(s)> are provisional and may be incomplete and subject to change*.
- Primary, secondary, and complementary cell suppression will be applied such that no tables, charts, figures, or other products publicly disseminated will disclose non-zero values of less than six (<6) observations or permit derivation through subtraction or other calculations from the combination of tables in a publication or permit disclosure when used in combination with other known data, without approval of HAVRS.
- Calculations such as rates that are based on less than six (<6) observations will be suppressed; Those based on less than twenty (<20) observations will include a statistical note. Recommended note: *Calculations based on <20 observations are statistically unreliable and should be interpreted with caution.*
- No sub-state geographic units (e.g., regions, county-equivalents, communities, etc.) will have a population less than twenty thousand (<20,000) without approval of HAVRS.
- I will give HAVRS at least ten (10) regular business days to review publications or other products derived from the data prior to public dissemination so HAVRS may ensure there is no disclosure of confidential information or to provide reasonable comment.
- I will cite HAVRS as the source of the data. Recommend citation: *Alaska Department of Health, Division of Public Health, Health Analytics and Vital Records Section. Alaska <Vital Statistics> or <Health Facilities Data Reporting Program>. Accessed <Month, Year>.*

3. Data Security, Notification of Breach, and Disposal Requirements

- I will use appropriate physical, technical, and administrative safeguards to prevent unauthorized use or disclosure of the data. This includes storing data in a secure location or facility; applying electronic encryption requiring unique passwords (minimum of 8 characters, containing uppercase, lowercase, numeric, and special characters); having defined policies and procedures related to data security.
- I will alert HAVRS immediately upon discovery of a breach if unauthorized use or disclosure of the data occurs.
- I will return, erase, or destroy the data upon completion of the approved use or termination of the DUA and will provide written notification to HAVRS confirming disposal.
- HAVRS-approved publications or other products derived from the data may be retained indefinitely.

VI. Duration and Amendment

This DUA is effective from the date it is signed by all parties and terminates on
or upon thirty (30) days' notice of termination by any of the parties, whichever occurs first. This DUA may be terminated at any time by any of the parties upon notification in writing by the party rescinding the agreement that they wish to terminate the agreement. This DUA may be amended at any time by any of the parties upon notification in writing by the party revising the agreement that they wish to amend the agreement.

Signature indicates agreement to abide by the terms and conditions of this DUA.

VII. Signatures

Principal Investigator (Primary recipient and data custodian)	Health Analytics and Vital Records (Data owner)
Name and Title: **Affiliation:** **Date:** **Signature:** X _____	**Name and Title:** **Affiliation:** **Date:** **Signature:** X _____

Investigator (Other recipient and data user)	Investigator (Other recipient and data user)
Name and Title: **Affiliation:** **Date:** **Signature:** X _____	**Name and Title:** **Affiliation:** **Date:** **Signature:** X _____

(Attach additional recipients and pages as needed)