

Data Disclosure Guidelines

Alberta Health and Wellness Role as Custodian of Administrative Health Data

Alberta Health and Wellness is custodian of extensive, but not exhaustive, administrative information about the Alberta health care system. As custodian of this valuable asset, Alberta Health and Wellness provides access to administrative data to support the data of various users (e.g., Alberta Health Services, academic researchers and others).

Information and Analysis Branch Role as Coordinator of Data Access Requests

All requests are made through the single point of entry, health.resdata@gov.ab.ca. Requests are reviewed by a team member of the Information and Analysis Branch and once the request requirements are defined it is assigned to an analyst. Once a research analyst has been assigned, you will be contacted to talk about the next steps of your request.

An initial meeting (in person or teleconference) between you and a designated **Research Resource Team (RRT)** may be required. The RRT is a virtual team of Alberta Health and Wellness cross-department staff, uniquely matched to the needs of the request (e.g., research content and data experts). **Data specifications will be determined before the data extraction takes place.**

Data Available for Research Purposes

Alberta Blue Cross Pharmacy Claims

- Only Seniors and Persons on Assistance and their dependents

Alberta Health Care Insurance Plan Payments

- Ministry payment for physician and other practitioner services

Alberta Health Care Insurance Plan Registry

- Ministry administration of the health insurance plan

Alberta Vital Statistics

- Government of Alberta are custodians

Ambulatory Care

Inpatient (Hospital Morbidity)

Long Term Care

Guiding Principles for Data Disclosure Under the *Health Information Act (HIA)*¹

Alberta Health and Wellness must comply with HIA principles:

1. Highest degree of anonymity for the persons who are the subject of the information;
2. Least amount of information disclosed that will meet the needs of the stated purpose; and,
3. Need to know refers to the disclosure of only necessary information to carry out research or responsibilities.

Highest Degree of Anonymity

1. Aggregate information is the most anonymous type of information. Non-identifying health information about groups of individuals with some common characteristic(s) ensures that the identity of an individual cannot be readily determined from the information.
2. Individually non-identifying information have identifiers removed so that the identity of the individual cannot be easily determined. The typical identifiers that are removed are: personal health number, hospital chart number, name, address, postal code and date of birth. Other attributes or combinations of attributes may also be considered identifying (e.g., rare disease, geographical isolation).

Individually-identifying information has a higher level of protection. The disclosure of individually-identifying data may require individual consents, or a Privacy Impact Assessment (PIA). A PIA is submitted directly to the Office of the Information and Privacy Commissioner (OIPC) prior to request for Alberta Health and Wellness data disclosure.

Least Amount of Data

When collecting, using or disclosing health information, a custodian must collect, use and disclose only the amount of health information that is essential to enable the requester to carry out the intended purpose. Requesters need to clearly explain their need for particular elements requested.

Need to Know

Requesters need to explain how the data will be used and for what purposes.

Request Information

Typical request information includes:

¹ The HIA is available on the Alberta Health and Wellness web site:

http://www.qp.alberta.ca/574.cfm?page=H05.cfm&leg_type=Acts&isbncln=9780779724758

http://www.qp.alberta.ca/574.cfm?page=2001_070.cfm&leg_type=Regs&isbncln=9780779736256

<http://www.health.alberta.ca/documents/HIA-Guidelines-Practices-Manual.pdf>

- Identify the project title and provide available documents (e.g., Letters of Intent, Proposals, Business Case, Ethics Application and Approval, PIA if required, etc.). Name the principal investigator (PI) or lead on the study or project who is the signature for agreements, etc.
- Name other contacts if appropriate (e.g., if the request is for a graduate student, the academic advisor is named as the PI).
- Provide the name of the organization, address, telephone, fax numbers and email address.
- Provide details on the study or project including:
 - Issues to be examined (e.g., research question)
 - Study population and approximate sample size expected (indicate whether the ethics committee requires individual consent)
 - Characteristics of the study group (e.g., age, diagnosis, etc.)
 - Unit of observation (e.g., individual, health service event, etc.)
 - Form in which the data is to be organized (e.g., summed across groups of individuals or calculated values)
 - Consent forms

Data Specification Development

The requester will work with the analysts at the initial meeting (and necessary subsequent meetings) to identify the data specifications.

Cost Estimate

Alberta Health and Wellness completes requests on a cost-recovery basis. Below are the rates for data extractions:

\$1000 /day – Administrative functions

\$1600 /day – Research

- A range of the expected cost will be estimated after an initial consultation.
- Cost adjustments may be needed if there are changes on the specifications.

Costs are for analyst time only and exclude meeting, communication and run time.

Time for Extract

Many data sources are created on an annual basis only, and are not available until several months after the end of the fiscal or calendar year. Requesters should account for some elapsed time to allow for data processing from the source (e.g., health authorities).

It is recommended that researchers contact the Information and Analysis Branch (health.resdata@gov.ab.ca) as early as possible in their process (i.e., letter of intent or

proposal stage). The RRT can assist with an understanding of what data is available and when.

Administrative Requirements

The requester will complete the administrative requirements for disclosure when the data product is ready, or shortly before. Disclosures of aggregate information may only require an invoice for the cost of collating the information. For most data disclosures, there will be a contractual Data Agreement with Alberta Health and Wellness (HIA section 54).

For its own records, and to meet HIA requirements, Alberta Health and Wellness documents the data disclosure. Alberta Health and Wellness may contact the requester in order to monitor compliance with the Agreement and legislation, including a check on data security measures.

Requester must inform Alberta Health and Wellness of publications and presentations based on data received from Alberta Health and Wellness, if required in the Agreement.

When the return or destruction of the data is required by the Agreement, the requester will return the data to the Information and Analysis Branch or provide evidence that destruction has occurred.

Contact

Alberta Health and Wellness
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