



TITLE

RESEARCH INFORMATION MANAGEMENT

SCOPE

Provincial

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1146

APPROVAL AUTHORITY

Corporate Services Executive Committee

INITIAL EFFECTIVE DATE

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SPONSOR

Vice President, System Innovations & Programs

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Not applicable

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October 16, 2022

NOTE: The first appearance of terms in bold in the body of this document (except titles) are defined terms – please refer to the Definitions section.

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OBJECTIVES

- To support Alberta Health Services' (AHS) commitment to **research** that has the goal of improving care, services, and/or systems in the health sector.
- To set out the requirements for the collection, use, and disclosure of **personal information** and **health information** (collectively referred to as 'information') for the purpose of research.
- To support the expected InfoCare behaviours of **AHS people** when handling information and to meet AHS' legal obligations as a public body holding personal information and as a custodian of health information.

PRINCIPLES

AHS recognizes the importance of research in fulfilling its vision of 'Healthy Alberta. Healthy Communities. Together.' AHS has a duty to protect the privacy and confidentiality of information in its custody and control. AHS is committed to the collection, use, and disclosure of information in its custody and control for research purposes provided such actions are in accordance with applicable legislation and AHS' mission, vision, and values, and policies and procedures. Information shall only be collected, used, and disclosed by **researchers** for approved research purposes.

APPLICABILITY

Compliance with this document is required by all Alberta Health Services employees, members of the medical and midwifery staffs, Students, Volunteers, and other persons acting on behalf of Alberta Health Services (including contracted service providers as necessary).

ELEMENTS

1. AHS Responsibilities

- 1.1 AHS shall grant the collection, use, and disclosure of information for the purpose of research in accordance with:
 - a) the *Health Information Act* (Alberta) (HIA) and the *Freedom of Information and Protection of Privacy Act* (Alberta) (FOIP); and
 - b) any conditions set by AHS and/or for health information, a **Research Ethics Board**.
- 1.2 The Vice President, System Innovations & Programs, or designate may authorize, in accordance with Section 1.1 of this Policy, the disclosure of information held in its custody to a researcher for the purposes of research.
- 1.3 AHS shall obtain the consent of an individual from whom additional information is being sought by a researcher. Researchers shall not contact that individual without the consent having first been obtained.

2. Repository Owner Responsibilities

- 2.1 A privacy assessment and/or Privacy Impact Assessment is required when a **repository** is created to facilitate future research or quality improvement initiatives.
- 2.2 A **repository owner** is designated with roles and responsibilities outlined in the *Privacy Impact Assessments* Policy.
- 2.3 Repository owners shall have in place, when required, Privacy Impact Assessments that set out administrative practices, technical and physical controls, and departmental processes for managing research requests.
- 2.4 Repository owners shall confirm that researchers have signed appropriate **disclosure agreements** with AHS before disclosing information to researchers.
- 2.5 When requested information is being disclosed directly to the researcher, the repository owner shall ensure that the researcher can access only the information set out in the research proposal as approved by the Research Ethics Board. Direct system access may be provided to the researcher in accordance with the access conditions established in the system's Privacy Impact Assessment.
- 2.6 For data extraction requests, repository owners shall not disclose additional health information **data elements** until the researcher has submitted an amendment approval letter from the Research Ethics Board for any information not covered in the original ethics approval.

- 2.7 Repository owners shall have a right to decline the request for information at its discretion even if the researcher has been authorized to receive the information.
- 2.8 Repository owners shall have a right to request that the information disclosed be returned, disposed of, or retained in accordance with applicable legislation, AHS policies and procedures, and contractual obligations.

3. Disclosure Agreements for Research Purposes

- 3.1 Disclosure agreements are required, in accordance with the HIA and FOIP, where information is disclosed by AHS for research purposes.
- 3.2 Disclosure agreements are not required for activities related to non-Research Ethics Board approved quality improvement, program evaluation, or education of health services providers.
- 3.3 Disclosure agreements, agreed to by the Principal Investigator listed on the Research Ethics Board approval, shall reference:
- a) the Research Ethics Board application containing the names of all the researchers and research team members who have access to the information;
 - b) the approved research proposal;
 - c) the Research Ethics Board approval date;
 - d) data elements being requested or directly accessed, if not included in the proposal;
 - e) conditions for if additional information will be collected from the individual;
 - f) conditions for if data transfer will occur; and
 - g) conditions for if **data matching** will occur.
- 3.4 In the disclosure agreement, AHS authorizes the researcher to collect, use, or receive information for research purposes in compliance with all applicable legislation, all conditions imposed by AHS, and all conditions imposed by the Research Ethics Board.

4. Fees

- 4.1 AHS may charge a fee for:
- a) preparing information for disclosure or performing data matching or other services;
 - b) making copies of information; and

- c) obtaining the consents required if the researcher is requesting additional information beyond that which is in the custody or control of AHS.

DEFINITIONS

AHS people means Alberta Health Services employees, members of the medical and midwifery staffs, Students, Volunteers, and other persons acting on behalf of AHS (including contracted service providers as necessary).

Data element means the smallest named item of data that conveys meaningful information or condenses lengthy description into a short code. Data elements may also be described as a “data field” in the structure of a database or as a specific column in a table in the database for the application.

Data matching means the creation of individually identifying health information by combining health information, whether identifiable or non-identifiable, from two or more sources without the consent of the individual who is the subject of the information.

Disclosure agreement means a standalone agreement with terms and conditions pertaining to the information disclosure or terms and conditions pertaining to the information disclosure incorporated into other forms of research-related agreements negotiated for the overall conduct of the research project, including, but not limited to, clinical trial agreements, sub-site agreements, or data/material transfer agreements. This agreement between the researcher and AHS ensures compliance with legislation, AHS policies and procedures, and any conditions imposed by AHS specifically to the research study.

Health information means one or both of the following:

- a) diagnostic, treatment, and care information; and
- b) registration information (e.g., demographics, residency, health services eligibility, or billing).

Personal information means recorded information, not governed by the *Health Information Act* (Alberta), of any kind stored in any format that identifies an individual including, but not limited to:

- a) address and contact information (including an identifying number or symbol assigned to an individual);
- b) race, ethnic origin, gender, or marital status;
- c) educational, financial, employment, or criminal history;
- d) opinions of others about the person;
- e) the image of a person on a photograph; and
- f) personal views and opinions of a person (except if these are about another person).

Repository means a collection of AHS information where the information is organized, made accessible to authorized users, protected and stored for specified legal retention periods. A repository includes, but is not limited to, individual repositories and data warehouses.

Repository owner means the individual(s) responsible for defining the processes and controls for the assessment, storage, security, privacy, and disposition of the information in a repository.

Research means an activity whose purpose is to contribute to the growing body of knowledge regarding health and/or health systems that is generally accessible through standard search procedures of academic literature. All research studies must be reviewed and approved by a Research Ethics Board. Research does not include activities related to quality improvement, program evaluation, or education of health services providers.

Researcher(s) means all eligible individuals conducting research (including employees, independent contractors, medical staff, midwifery staff, other health care professionals, students, and volunteers), employed by, appointed by, or representing AHS, or individuals (including non-employees listed on Research Ethics Board approved studies as research team members) using AHS resources to conduct research.

Research Ethics Board means a board or committee designated under the *Health Information Act* (Alberta) which is responsible for assessing the ethics of individual research proposals, requiring or waiving individual consents, and ensuring the researcher applies adequate safeguards to protect the identity of the individuals.

REFERENCES

- Alberta Health Services Governance Documents:
 - *Collection, Access, Use, and Disclosure of Information Policy* (#1112)
 - *Delegation of Authority and Responsibilities for Compliance with FOIP and the HIA Policy* (#1108)
 - *Information Classification Policy* (#1142)
 - *Intellectual Property Policy* (#1137)
 - *Official Records Destruction Procedure* (#1133-02)
 - *Privacy Impact Assessments Policy* (#1145)
 - *Privacy Protection and Information Access Policy* (#1177)
 - *Records Retention Schedule* (#1133-01)
- Alberta Health Services Resources:
 - *Clinical Information Sharing Approach*
- Non-Alberta Health Services Documents:
 - *Freedom of Information and Protection of Privacy Act* (Alberta)
 - *Health Information Act* (Alberta)

VERSION HISTORY

Date	Action Taken
October 16, 2019	Revised
Click here to enter a date	Optional: Choose an item