
Safeguarding Data

**For Evaluation and Quality
Improvement**

**A standards guide to protect the security,
privacy, and confidentiality of evaluation and
quality improvement data**

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Background

Alberta Health Services employees are responsible for ensuring that information they collect for evaluation and quality improvement comply with ethical standards. This document is a standard guideline outlining how to protect the security, privacy, and confidentiality of patient and provider information within the context of evaluation and quality improvement projects.

The document was originally developed by Workforce Research and Evaluation, AHS, to help staff interpret various AHS policies and Acts (e.g., *Health Information Act* of Alberta, *Freedom of Information and Protection of Privacy Act*) within the context of activities associated with evaluation and quality improvement projects. The standards and processes were reviewed and approved August 2013 by Information & Privacy, Alberta Health Services, for accessing, collecting, and/or reporting patient and provider data in a safe and secure manner. The document will be updated regularly to ensure compliance with new policies and guidelines.

It is expected that all RPI members are familiar with the document and comply with the standards outlined.

Accepted: August 15, 2013

Updated: August 29, 2013

Updated: January 28, 2015

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Last updated July 5, 2017.

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This resource has been developed by Research, Innovation and Analytics of Alberta Health Services.

Introduction

About Alberta Health Services– Research, Innovation and Analytics (RIA)

The Alberta Health Services (AHS) RIA Portfolio has a broad mandate to provide consistent and meaningful learning through effective and efficient research and rigorous evaluation. These activities are at the heart of the organization’s culture and deliver the fuel that drives consistent high performance and learning.

About Research Priorities and Implementation (RPI)

As part of RIA, Research Priorities and Implementation (RPI) consists of the following expert teams designed to enable and enhance quality patient-oriented research and evaluation.

Engagement, Education and Capacity is a provincial service that develops and delivers research learning opportunities in partnership with academic and provincial research and innovation institutions. Through the Assistant Scientific Directors (ASDs) in the research arm of the Strategic Clinical Networks (SCNs), this operation collaborates with the scientific community to identify and support scientific rigour, best practice, and advancement of research priorities within AHS.

Evaluation Services is a provincial service that supports a rigorous evaluation approach and skill set to support evidence-informed decision making for clients throughout AHS that will help inform and improve practice and patient care.

Knowledge for Change is an evidence-based knowledge translation science. Practice supports include training, academic-quality grant and project support, KT plans, knowledge brokering, synthesis, decision support, and dissemination expertise, including advice on implementation.

Research Facilitation is a provincial service that provides rigorous hands-on expert consultation and support for approved projects pre-submission and post award that have been endorsed by the dyadic leaders for the SCNs and the operational leaders for clinical departments.

Workforce Research and Evaluation is a provincial service that conducts joint research and evaluation projects to inform the effective use of the clinical workforce and the design of integrated collaborative service delivery models.

The document is to help staff interpret various AHS policies and Acts (e.g., *Health Information Act of Alberta, Freedom of Information and Protection of Privacy Act*) within the context of activities associated with evaluation and quality improvement projects.

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These guidelines apply to all RPI projects and activities related to the collection, use, and control of both qualitative and quantitative information. All RPI staff and affiliates are required to adhere to these standards.

Purpose

This document outlines standard processes in accordance with Alberta Health Services (AHS) policies and guidelines applicable to the collection and handling of all data to guide the data-related activities and practices of Research Priorities and Implementation (RPI) employees.

Statement

RPI complies with all AHS policies and practice standards to protect the security, privacy, and confidentiality of patient and employee data collected or obtained for evaluation and quality improvement (QI) purposes. This document outlines standards for data-related activities and processes applicable to most evaluation and QI projects to ensure the maximum protection and safe use of this data.

Applicability

These guidelines apply to all RPI projects and activities related to the collection, use, and control of both qualitative and quantitative information. All RPI staff and affiliates are required to adhere to these standards.

Processes

1. Classify the project or activity

- 1.1 Employees must determine whether the project or activity planned is research, QI, or evaluation.
- 1.2 Use the ARECCI Ethics Screening Tool. The ARECCI Screening Tool assesses the risk of the project and indicates whether a secondary review is required (depending on the results).
- 1.3 If the project is research, follow research guidelines in the AHS Research Information Management #1146. If the project is evaluation or QI, follow the guidelines in this document. If your activity or project type is not included in this document, contact the AHS Privacy Office for further instructions.

2. Collecting and obtaining evaluation or QI data

- 2.1 **Applications.** These processes apply to established data collection methods, including, but not limited to, paper or electronic surveys, face-to-face or telephone interviews, chart reviews and abstracting, and electronic access of the AHS databases, records, or reporting systems.
- 2.2 **Individual and group interviews, and surveys.**
 - **Information Sheet.** Signed informed consent is not mandatory for evaluation or QI data collection purposes. However, an information sheet about the project

is needed that states what data will be collected and why, what the data will be used for, assurances of confidentiality, that aggregate data will be provided to all participants, and the legal authority for collection (e.g., *Health Information Act* or *Freedom of Information and Protection of Privacy Act*). If it is necessary to obtain participants' Personal Health Number, the information sheet needs to clearly state that this is for data linkage purposes only.

- **Individual and group interview process.** Inform all interview participants of the project and what their participation entails prior to or at the start of the interviews by handing out the information sheet or reading it aloud. In either situation, participants must be informed that they may refuse to participate at any time if they wish to do so. Record interviews to assist with analysis. Consent to record the interview must be included at the beginning of the recording. The audio recording must be deleted from the device and stored temporarily on the AHS network drive. Access to these audio files must be limited to those who need to know.
- **Surveys.** For survey participants, include the information sheet as the first page of the survey. For online surveys, ensure the information sheet clearly presents the

option for the participant to proceed with or exit the survey.

- **Templates.** See Appendices A, B, and C for standard information sheets for *staff*, *patient*, and *provider* interviews/surveys respectively, which are approved by the AHS Privacy Office for RPI. Any significant modifications to the content in Appendices A, B, and C require review and approval from the Privacy Office prior to use.
- **Use of email.** Do not use email to survey, collect, or obtain any personal information from any individual, patient, or source outside of AHS. See 6.4 for the definition of non-AHS email.

2.3 Obtaining data from AHS databases and other electronic sources including patient charts.

- Do not collect or access electronic data without prior approval of the AHS Service Manager or Repository Owner. Electronic data includes individual AHS department/entity; Health Information Management (HIM); and Data Integration, Measurement & Reporting (DIMR).
- The data use agreement with the Repository Owner must be followed while accessing or using data.

- When obtaining data from an AHS database (such as DIMR repository), completely de-identify all records into non-identifying¹ information (by removing PHN and other identifying information of the patients) before it is downloaded from the DIMR repository and stored on the RPI unit shared drive for further analysis. Data files that link identifying information to non-identifying unique patient numbers may be created for data linking purposes. Store such files on the secure DIMR server and delete them after the data work is complete.

3. Data Storage

- 3.1 **Applications.** Office-based and computer storage of data in physical and electronic forms.
- 3.2 All AHS evaluation or QI data is stored on the unit and accessible only by RPI employees, all of whom have signed AHS confidentiality agreements and are bound by research/evaluation ethics standards for the handling of sensitive data.
- 3.3 As soon as employees return to the RPI site from data collection, they must ensure the hard copies of data are locked in their respective file cabinets and the electronic data is uploaded onto the secure AHS network drive and deleted from the recorder.

¹ “Non-identifying: When used to describe health information, means that the identity of the individual who is the subject of the information cannot be readily ascertained from the information. Non-identifying information includes statistical information about groups of individuals and individual information that is collected, used, and disclosed in a way that makes it anonymous. By removing an individual’s name and personal identifiers before information is disclosed from information or records that were identifiable, and by not providing other contextual information, the information could essentially become non-identifying information” (AHS Collection of Health Information Notices, IPO#21013-0004, p. 5).

The responsible employee will turn all interview transcripts into non-identifying data, as appropriate.

- 3.4 Returned surveys or collected data are stored in a secured cabinet within the RPI unit. Original copies of the returned surveys are retained and destroyed as outlined in Section 7. An electronic data file is created by entering the survey and unique study ID for each study subject or participant. This file is stored on the secure RPI shared network drive.
- 3.5 Electronic files of original or processed/analyzed data cannot be stored locally in employees' workstations, non-AHS computers, external drives, or removable or portable storage (such as flash drives and disks) except when the data is in transition from collection to the RPI office.

4. Data access, use, and disclosure

- 4.1 **Applications.** Access to evaluation or QI data collected or obtained by RPI.
- 4.2 Only RPI employees and contracted affiliates can have access to the evaluation or QI data stored on the shared RPI network drive. The network drive is a secured storage maintained by AHS IT department limiting access to RPI employees only.
- 4.3 Evaluation or QI data collected or obtained by RPI cannot be accessed by or disclosed to anybody outside of RPI. Any exceptions are reviewed case by case, and any provision of data access, new uses of data by AHS, or disclosure of data must be in compliance with AHS policies. Appropriate agreements must be in place prior to obtaining data or commencing data collection.

4.4 **Transcriptionists.** RPI have contracts with transcriptionists to transcribe recorded interviews for analysis. Transcriptionists are affiliates of AHS and all have signed confidentiality agreements (see Appendix D) outlining these conditions:

- Data recordings and transcripts must be transmitted via a secure AHS email address where possible.
- For those transcriptionists who do not have an AHS email address, encrypted emails are required for all data transmissions. Transcriptionists will not disclose the contents of the interview recordings or transcripts with anyone other than the person requesting the transcription services. See 6.4 for data encryption.
- Transcriptionists must delete all interview data from all places, including their email and computer folders, as soon as they have confirmed receipt by RPI.

4.5 RPI consultants are responsible for reviewing the transcript for accuracy once it has been received and then confirming with the transcriptionist that it can now be deleted from his/her records and storage. Consultants are also responsible for deleting the files from their email folder once the transcripts have been returned.

4.6 Any data disclosed outside of AHS must be in non-identifying form and accompanied with a letter that describes the purpose of the request, that AHS is disclosing the information for that purpose, and that the recipient has agreed to not re-engineer the data and to not attempt to contact individuals.

5. Data usage and linking

- 5.1 **Applications.** An outline of the scope and purpose of data usage and linking of data.
- 5.2 The data in RPI's possession can be used only for evaluation or QI purposes directly serving the needs of AHS except in the case of externally sponsored projects. The usage of the data must be according to specifics outlined in the project plan. The data cannot be used for any purposes that are not clearly stated in RPI evaluation or QI projects. In the case of non-AHS sponsored projects, or when data is obtained from other AHS or external owners, the data user agreement with data custodians must be strictly followed while handling or using such data.
- 5.3 Any data linking must be performed in a secured manner. To link RPI collected or obtained evaluation or QI data with AHS administrative databases where DIMR is the custodian (such as discharge abstract database), the data is first uploaded to the DIMR repository server and then linking is performed in a secure server environment using server applications and tools. The linked file is stored on the DIMR repository and the linked data is exported to the RPI network drive by stripping identifying information (such as health numbers) from all records. The following data may be linked:
- Demographic information, such as age, gender, province/territory of PHN, region of residence, postal code.
 - Health information, such as admission and discharge dates, time, and types; and diagnosis and procedure codes, dates, and types.

- Hospital sites, units, locations, provider profiles, staffing, workforce utilization, and cost information.

- 5.4 If data linking is performed locally, a separate file containing linking information is created and stored in a different folder. The linked dataset is stripped of the original identifying information used to match individuals or entities.

6. Data transmission and transport

- 6.1 **Applications.** Physical movement of data in any form, transmission of electronic data, and data email and fax policy.
- 6.2 Collected survey forms and recording devices containing any data must be secured in a closed non-transparent/non-translucent container (e.g., briefcase) during transport. Mark the container "confidential" and attach AHS contact information (e.g., name, business address, and telephone number). During transport, the data container must be under the direct control of authorized persons throughout the travel period. When using a privately owned vehicle (including rental car), authorized persons must secure all information in the vehicle's trunk (or equivalent) during transport: the information cannot be visible or left unattended. Authorized persons are solely responsible for security and control of the container and data while off-duty.
- 6.3 Electronic data can be transmitted within AHS network only, between AHS/RPI server and network drives. Data files can be sent to employees' AHS email addresses or AHS fax numbers when necessary. Data cannot be sent out of AHS's secure network, emailed, or faxed without completely de-

identifying the records. However, this policy is modified when contracting the services of an external transcriptionist (see Section 4.4 for details).

- 6.4 Use encryption when sending data via email to all non-AHS email addresses. Use only your AHS email to send data. Encryption technology must be manually added when emailing data to an outside email account by using the AHS guidelines on encryption. Email within the AHS network does not require encryption. The *firstname.lastname@albertahealthservices.ca* indicates the connection is secure. AHS provides guidelines on how to encrypt email and change sensitivity setting in MS Outlook. See *Guide to Email Encryption (AHS)* for details (link provided in Section 10).

7. Data retention/archiving and disposal

- 7.1 **Applications.** General procedures for archiving data, data retention period, disposal of data in physical and electronic forms.
- 7.2 All evaluation or QI data remains on the secured RPI shared drive for the project duration or for as long as needed to complete data analysis. Once data analysis is complete, all data must be archived following the standard process outlined in this document.
- 7.3 Retain all files (electronic and paper) for five years from the project end date. After a project is completed, move all electronic files to an Archive folder with the date of destruction in the name (e.g., Project X Destruction Date 31-Dec-2019). For paper

files, write the date of destruction on the folder's exterior and store the files in a locked physical archive.

- 7.4 After the analysis is completed, archive all data on the shared drive and retain it in accordance with AHS's data retention policy (Classification Code 1420: retain for 5 years after the project is closed) for evaluation and QI data.

8. Data disclosure and dissemination

- 8.1 Evaluation or QI reports or data can be disseminated through publications in professional or scholarly journals. To maintain the privacy and confidentiality of participants, information that can potentially be used to identify individual patients, providers, or AHS employees will not be disclosed or published in articles or reports.
- 8.2 Original evaluation or QI data cannot be disclosed to external parties. Any exception to this policy must be reviewed and approved by the AHS Privacy Office.

9. Reporting breach

- 9.1 **Applications.** What to do when standard processes are not followed.
- 9.2 Any failure to observe the processes outlined in this document—whether deliberate or accidental—must be promptly reported to the RPI director or to the AHS Information & Privacy Office. Non-compliance with this policy may result in disciplinary action up to and including termination of employment or appointment.

10. Relevant AHS policies, procedures and guidelines

Access to Information (Physical, Electronic, Remote) (Document #1105)

<https://extranet.ahsnet.ca/teams/policydocuments/1/clp-ahs-pol-access-information.pdf>

Alberta Health Services Information and Privacy Office at privacy@albertahealthservices.ca or

<http://insite.albertahealthservices.ca/1189.asp>

ARECCI Screening Tools

www.aihealthsolutions.ca/arecci/screening

Collection, Access, Use, and Disclosure of Information (Document #1112)

<https://extranet.ahsnet.ca/teams/policydocuments/1/clp-ahs-pol-collection-access-use-disclosure-information.pdf>

Guide to Email Encryption (AHS)

<http://insite.albertahealthservices.ca/Files/tms-it-email-guid-encryption.pdf>

Information Security and Privacy Safeguards (Document #1143)

<https://extranet.ahsnet.ca/teams/policydocuments/1/clp-ahs-pol-information-security.pdf>

Records Destruction (Document #1133-02)

<http://insite.albertahealthservices.ca/Files/cpd-prd-im0702-approved-records-destruction.pdf>

Records Management (Document #1133)

<https://extranet.ahsnet.ca/teams/policydocuments/1/clp-ahs-pol-records-management.pdf>

Records Retention Schedule (Document #1133-01)

<http://insite.albertahealthservices.ca/legal-privacy/tms-lp-ahs-retention-schedule.pdf>

Research Information Management (Policy #1146)

<http://insite.albertahealthservices.ca/Files/cpd-pol-approved-research-info-management.pdf>

Standards of Practice for Survey & Evaluation Services

<http://www.albertahealthservices.ca/Infofor/if-hp-pg-standards-of-practice-for-survey-and-evaluation-services.pdf>

Transmission of Information by Facsimile or Electronic Mail (Document #1113)

<https://extranet.ahsnet.ca/teams/policydocuments/1/clp-ahs-pol-transmission-information.pdf>

Appendix A

Healthcare Provider Interview Script (EXAMPLE)

Overview of Healthcare Provider Participation

This interview is part of an (evaluation/quality improvement) to better understand **BRIEF EXPLANATION OF PROJECT PURPOSE HERE**.

[RPI operation] at AHS is conducting interviews with various healthcare teams (in **SETTING**) in Alberta to determine:

- What is working well...
- What areas need improvement...
- What impact your service has made...

Methodology

We will be conducting individual and group interviews (30–90 minutes) at each site. The interviews will be recorded to assist us with analysis. Information collected from these interviews is authorized under section 20(b) and 27(1)(g) of the *Health Information Act* of Alberta and/or section 33(c) of the *Freedom of Information and Protection of Privacy Act*.

Confidentiality and Ethics

AHS will do everything we can to protect your privacy and we agree to collect, access, use, and disclose information as per the *Health Information Act*. The information collected is authorized under section 20(b) and 27(1)(g) of the *Health Information Act*. AHS ensures compliance with ethical standards.

- You have the right to decline our invitation to participate at any time.
- No names or any other identifying information will be attached to your interview to protect the anonymity of the participants.
- Data will be protected in accordance with AHS policies.
- Raw data from interviews will not be shared beyond the core evaluation team. Data that is shared beyond the evaluation team will be pooled with other respondents' data so that your responses are not identifiable.
- Every effort will be made to ensure you are not identifiable in any written materials arising from the study.

For further information, please contact **EVALUATOR'S NAME, AHS JOB TITLE/ROLE, EMAIL, PHONE NUMBER HERE**

Thank you for participating in the interviews!

Appendix B

Patient Survey Script (EXAMPLE)

Brief Project Title

BRIEF EXPLANATION OF PROJECT PURPOSE HERE

What do we ask you to do?

We ask that you complete a brief survey. This should take no more than **TIME HERE** to complete. The information will be used to **BRIEF GOAL HERE**.

Your participation is voluntary. You do not have to complete the survey. This will in no way affect the care you receive.

Confidentiality and Ethics

AHS will do everything we can to protect your privacy and we agree to collect, access, use, and disclose information as per the *Health Information Act*. The information collected is authorized under section 20(b) and 27(1)(g) of the *Health Information Act* of Alberta and/or section 33(c) of the *Freedom of Information and Protection of Privacy Act*. AHS ensures compliance with ethical standards.

- You have the right to decline our invitation to participate at any time.
- Please do not put your name in the survey since we want to protect your privacy.
- No names or any other identifying information will be attached to the surveys to protect the anonymity of the participants.
- Data will be protected in accordance with AHS policies.
- Raw data (surveys) will not be shared beyond the core evaluation team. Data that is shared beyond the evaluation team will be pooled with other respondents' data so that your responses are not identifiable.
- Every effort will be made to ensure you are not identifiable in any written materials arising from the study.
- You have agreed to participate by completing and returning the survey.

FOR PAPER SURVEYS: *If you choose to complete the survey, please place the survey in the envelope, seal the envelope, and return it to a healthcare provider or put it in the drop box provided. By completing and returning the survey, you are giving us permission to use your survey information.*

For further information please contact **YOUR NAME, JOB TITLE/ROLE, EMAIL, PHONE NUMBER HERE**

Thank you for participating in the survey!

FOR ONLINE SURVEYS: *"I have read and understand the purpose of this survey" [click YES to continue] [click NO to exit survey]*

Appendix C

Provider Survey Script (EXAMPLE)

Overview of Provider Participation

This survey is part of an evaluation/quality improvement to **EXPLAIN PROJECT GOALS HERE**. **[RPI operation]** at AHS is administering surveys with **EXPLAIN PARTICIPANTS HERE** in Alberta to determine:

- **LIST OBJECTIVES HERE**

Methodology

We will be administering surveys, which should take approximately **TIME HERE** to complete.

Confidentiality and Ethics

AHS will do everything we can to protect your privacy and we agree to collect, access, use, and disclose information as per the *Health Information Act*. The information collected is authorized under section 20(b) and 27(1)(g) of the *Health Information Act* of Alberta and/or section 33(c) of the *Freedom of Information and Protection of Privacy Act*. AHS ensures compliance with ethical standards.

- You have the right to decline our invitation to participate at any time.
- Please do not put your name in the survey since we want to protect your privacy.
- No names or any other identifying information will be attached to the surveys to protect the anonymity of the participants.
- Data will be protected in accordance with AHS policies.
- Raw data (surveys) will not be shared beyond the core evaluation team. Data that is shared beyond the evaluation team will be pooled with other respondents' data so that your responses are not identifiable.
- Every effort will be made to ensure you are not identifiable in any written materials arising from the study.
- You have agreed to participate by completing and returning the survey.

For further information please contact **YOUR NAME, JOB TITLE/ROLE, EMAIL, PHONE NUMBER HERE**

Thank you for your participation!

FOR ONLINE SURVEYS: “I have read and understand the purpose of this survey” [click YES to continue] [click NO to exit survey]

Appendix D

Confidentiality Agreement with Transcriptionists



This agreement is between you and Alberta Health Services. By authorizing you will be subject to legally binding terms and conditions. Carefully read all of the terms and conditions set out below. Signing this agreement indicates your acceptance of the terms and conditions of this agreement and that you intend to be legally bound by them. If you do not agree with the terms and conditions, you are responsible for advising the AHS Information & Privacy Office.

CONFIDENTIALITY AGREEMENT

Whereas:

1. Alberta Health Services is a Custodian as defined in the *Health Information Act*, ("HIA"), and as a Public Body as defined in the *Freedom of Information and Protection of Privacy Act*, ("FOIP"), and as such is subject to both Acts.
2. The HIA defines an Affiliate of a Custodian as an employee, a health care provider with privileges, a volunteer or a student of the Custodian or those who provide services under contract for a Custodian.

I AGREE THAT:

3. I am an affiliate of Alberta Health Services (as defined in the HIA).
4. All Health Information (as defined in the HIA), all Personal Information (as defined in the FOIP, or any other privacy legislation in effect), that I collect, use, retain and/or disclose in my role as an Affiliate of Alberta Health Services is private and confidential.
5. It is my responsibility as an Affiliate of Alberta Health Services to know and follow relevant information, privacy and security policies in effect in Alberta Health Services.
6. I will take all reasonable steps to act in accordance with applicable Alberta Health Services policies, codes of conduct, bylaws, collective agreements, the HIA, the FOIP, and any other privacy legislation in effect and to keep private and confidential and prevent the unauthorized collection, use and/or disclosure all Health Information and/or Personal Information that I come into contact with in my role as an Affiliate of Alberta Health Services. Such steps include, without limitation, taking reasonable security precautions against such risks as unauthorized access, collection, use, disclosure, alteration or disposal.
7. If I knowingly collect, use and/or disclose Health Information or Personal Information in my role as an Affiliate of Alberta Health Services in contravention of Alberta Health Services policies, codes of conduct, bylaws, collective agreements, the HIA, the FOIP, and any other privacy legislation in effect, I may be subject to disciplinary action, termination, and/or guilty of an offence under the HIA, the FOIP, and any other privacy legislation in effect.
8. I am responsible to keep confidential all Health Information and Personal Information for as long as required by the HIA, the FOIP or other relevant privacy legislation in effect. I agree that the obligations of confidentiality shall survive the termination of this Agreement.
9. I agree to notify Alberta Health Services as soon as reasonably possible if I am aware of a breach of this agreement.
10. I agree to return all Health Information and all Personal Information when requested by Alberta Health Services or if requested by Alberta Health Services to destroy the Health Information and Personal Information given to me by it in my possession in accordance its record management policies.

By signing below I accept the terms and conditions of this agreement and intend to be legally bound by them.

Name: _____ Employee #: (if applicable) _____

Site & Department: _____ Date: _____

Signature: _____

