



**Alberta Perinatal Health Program
PeriLink^{AB}**

Information Repository User Manual

April 2014

1. General

This document provides the standard description of the procedures that the **Alberta Perinatal Health Program (APHP)** will adhere to for safeguarding personally identifiable information within PeriLink^{AB}.

Purpose

The purpose of this document is to assist **Selikke Janes-Kelley, Executive Director of the Alberta Perinatal Health Program (APHP)** in understanding her responsibilities and duties to protect the information in PeriLink^{AB} and to ensure that changes to the repository that may affect the security and privacy controls are reported to the Office of the Information and Privacy Commissioner (OIPC). This document outlines the policies and procedures for collection, use and disclosure of health information to ensure procedures and controls meet the privacy requirements set forth by Alberta Health Services (AHS), including the preparation and submission of a Privacy Impact Assessment (PIA) to the OIPC.

This document will address the general principles of data management, data collection, use and disclosure, retention and disposal of data in the custody of the APHP. The procedures and policies outlined in this document apply to all permanent, casual and contract employees within the APHP and within AHS or Covenant Health that may come in contact with health information stored in PeriLink^{AB}.

Any group or individuals that make requests for use or disclosure of data in the custody of the APHP are subject to these policies and procedures for use and disclosure of information.

Delegation

Selikke Janes-Kelley, Executive Director of the Alberta Perinatal Health Program (APHP), and the Information Repository Owner, delegates the responsibility for defining the procedures and controls for accessing, storing, security, privacy and disposition of the information in the repository to **Nancy Aelicks, Information Management and Research Coordinator of the APHP**.

Sign-Off of Information Repository User Manual

This **Information Repository Owner User Manual** has been reviewed and signed-off by the following individual(s):

Selikke Janes-Kelley, Executive Director of the APHP
Nancy Aelicks, Information Management and Research Coordinator of the APHP,

This document will be reviewed **annually**.

2. PIA Maintenance and Compliance

PIA Maintenance

Regular Maintenance

The **Executive Director of the APHP** will review the **APHP PeriLink^{AB}** PIA and all Amendments associated with the PIA annually.

The purpose of the review is to ensure that the PIA and its Amendments continue to accurately reflect the currency of the information flows, legal authorities, and access controls associated with the repository. The information repository owner will ensure differences between the PIA and the repository are documented and an Amendment for the PIA prepared and forwarded to the Information & Privacy Office for review, feedback and subsequent submission to the OIPC. If there are significant differences between the repository and what is described in the PIA, a new PIA will be prepared and forwarded to the Information & Privacy Office for submission to the OIPC.

Major or Significant Change

Prior to the implementation of a major or significant upgrade or change to the repository the **Information Management and Research Coordinator** or designate will contact the Information & Privacy Office to determine whether an Amendment to the repository PIA is sufficient or if a new PIA is required. The **Information Management and Research Coordinator**, or designate, will ensure the PIA Amendment or new PIA is prepared as per the recommendations of the Information & Privacy Office.

PIA Tools

AHS Privacy Impact Assessment Webpage -

<http://insite.albertahealthservices.ca/4314.asp>

PIA and Research Intake System

<http://acbnet.ad.cancerboard.ab.ca:81/piams/intake/>

PIA Intake Tool –

<http://acbnet.ad.cancerboard.ab.ca/piams/intake/newintake.php>

PIA Amendment Tool –

<http://acbnet.ad.cancerboard.ab.ca/piams/intake/amendment.php>

Accepted PIA Registry –

<http://acbnet.ad.cancerboard.ab.ca/piams/intake/piareg.php>

PIA Resource Documentation -

<http://acbnet.ad.cancerboard.ab.ca/piams/intake/resources.php>

Send a message –

<http://acbnet.ad.cancerboard.ab.ca/piams/intake/intake.php>

Reference:

Privacy Impact Assessments Policy 1145 –

<http://www.albertahealthservices.ca/Policies/ahs-pol-privacy-impact-assessments.pdf>

Transmission of Information by Facsimile or Electronic Mail Policy 1113 –

<http://www.albertahealthservices.ca/Policies/ahs-pol-transmission-information.pdf>

PIA Compliance

Information Repository Owner Review

Annually, the **Information Management and Research Coordinator** will review the security and privacy controls described in the PIA and confirm that these controls are being adhered to. Where the controls are not compliant with the PIA, the **Executive Director of the APHP** or an individual assigned by the Information Repository Owner, will immediately take action to correct the non-compliance.

Reference:

Privacy Impact Assessments Policy 1145

<http://www.albertahealthservices.ca/Policies/ahs-pol-privacy-impact-assessments.pdf>

PIA Annual Compliance Support Document

http://acbnet.ad.cancerboard.ab.ca/piams/documentation/pia_documentation/PIA_Annual_Compliance_Support_Doc_0010.pdf

3. Training

The **Alberta Perinatal Health Program** complies with AHS' Information & Privacy and IT Security and Compliance on all related training and compulsory refresher courses. Access will be granted upon confirmation of completion of the repository training as well as AHS Privacy and Security Awareness training.

Reference:

Information & Privacy – Education & Training

<http://insite.albertahealthservices.ca/1213.asp>

Organizational Orientation

<http://insite.albertahealthservices.ca/4351.asp>

Organizational Orientation Registration

<https://www.cvent.com/events/alberta-health-services-organizational-orientation/registration-38f56ae450c349e8820167683c3e2a06.aspx>

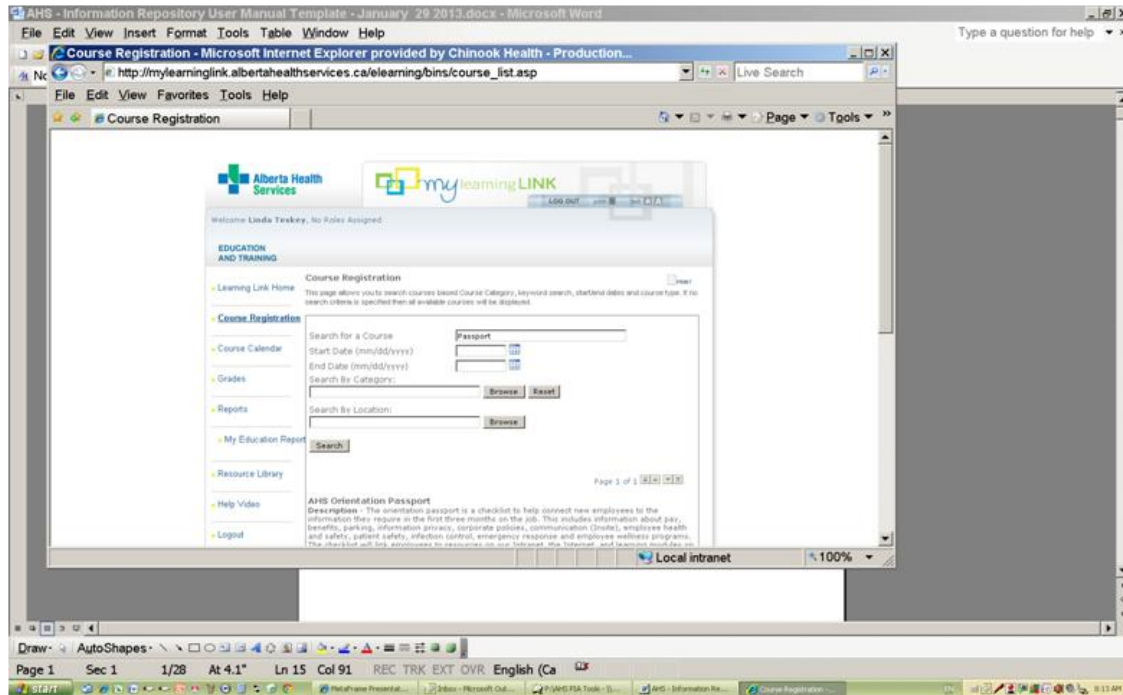
Orientation -

Employee orientation now takes place online. Online orientation consists of two parts:

Narrated Orientation -

[Narrated orientation](#): completed before a new employee's first day of work. New employees **DO NOT NEED NETWORK ACCESS** to complete the narrated orientation.

Orientation Passport -



Once new employees have completed the narrated orientation, they will have 90 days to complete their Orientation Passport. Certain aspects will need to be completed the 1st week of employment, while others at specified times during the 90 days.

The Passport: provides links to AHS directives, safety, training and other information such as email access and news. New employees must register for their passport on [MyLearningLink](#) (use search term: AHS Orientation Passport).

New employees will receive a notification email about orientation and instructions for accessing the narrated version as part of their on-boarding process in e-People.

- [New online orientation: manager frequently asked questions](#)

AHS will continue to provide dates, times and locations for local union representatives to share information with new employees until all areas have transitioned to e-People.

- [Union presentations for new employees \(dates, locations\)](#)

It is the responsibility of the hiring manager to register new AHS employees not on e-People Orientation. If new employees are unable to attend the in-person session, they can still access the AHS Organizational Orientation [self-study module](#).

Unit Clerks and nursing staff from individual hospitals performing direct data entry into PeriLink^{AB} would receive AHS Privacy and Security Awareness training and orientation at the time of hire.

- [Orientation Registration](#)

Course Objectives: After completing this orientation passport the new employee will:

1. Be able to describe AHS's mission, vision, goals and values
2. Know how to access information about payroll, benefits, parking
3. Know how to log-on and search courses in MyLearningLink
4. Be familiar with information contained in key corporate policies
5. Be able to describe the purpose of the Code of Conduct
6. Be familiar with their rights and responsibilities as an employee of AHS with regards to health and safety
7. Be familiar with employee wellness initiatives
8. Know where to find information about employee tools, AHS teams and departments and about AHS on Insite
9. Know how to respond to emergencies (as per the emergency response codes)
10. Understand the importance of and their role in protecting confidential information in accordance with the HIA and FOIPP acts
11. Understand their role in preventing infections and be able to describe and demonstrate 'Routine Practices'

Target Audience - All new AHS employees.

Time needed to complete course: three months.


Prerequisites: None. Recommend that new employees complete the AHS Orientation e-learning module before accessing the passport.

For more information about the content of this course, please contact:

carrie.farnell@albertahealthservices.ca

Course Prerequisites - None

Certificate Prerequisites - None

Session	Date	Location	Instructor	Enrolment		
10001	Tue Feb. 5, 2013 1:00AM - Wed Feb. 5, 2014 11:59PM	Online		160 out of Unlimited		

For questions about orientation, please contact carrie.farnell@albertahealthservices.ca

Information Repository Training

The **Information Management and Research Coordinator** will require users to complete training session(s) for the proper access and use of the repository. Persons who have been granted access to health and personal information in PeriLink^{AB} are responsible to protect the confidentiality and privacy of the individuals who are the subject of the information, to use the information responsibly and appropriately and to maintain the integrity and accuracy of the information.

All users must have AHS network access with an AHS / Covenant Health valid password prior to being granted access to PeriLink^{AB}. Each user is provided with a copy of the PeriLink^{AB} Data Entry Manual and provided training by an experienced user prior to being given access to PeriLink^{AB}. The PeriLink^{AB} Data Entry Manual describes the responsibilities and duties to protect the information in the PeriLink^{AB}.

Information Repository Upgrade Training

If there is a major upgrade to the repository, the **Information Management and Research Coordinator** will require all users to complete additional training explaining changes to the repository.

AHS Privacy and Security Awareness Training

It is the responsibility of the **Manager** for each user to ensure that all users have completed current AHS Privacy and Security Awareness Training, including annual refresher training prior to requesting and being granted access to the **PeriLink^{AB}**. Training is available to staff in the following methods:

- Online video – ‘*Basic Privacy & Security: Collect it. Protect it*’ - is located at: <http://insite.albertahealthservices.ca/1213.asp>
- Staff may also complete the AHS Human Resources Services Compulsory Education Module online at: <http://insite.albertahealthservices.ca/Files/hr-compulsory-education-ace-workbook.pdf>
- My Learning Link: <http://mylearninglink.albertahealthservices.ca> – Information Privacy and IT Security Awareness Module.
- AHS Website: <http://www.albertahealthservices.ca/3962.asp>

The **Manager for each user** will be responsible for ensuring that all users whose AHS Privacy and Security Awareness Training is kept current.

Reference:

Information & Privacy – Education and Training

<http://insite.albertahealthservices.ca/1213.asp>

Information Security and Privacy Safeguards Policy 1143

<http://www.albertahealthservices.ca/Policies/ahs-pol-information-security.pdf>

4. Research

Any facility or individual interested in perinatal health may request data from PeriLink^{AB} for research. Before approval is granted, the APHP will evaluate requests according to security and confidentiality of data, scientific merit, public interest and value, and workload commitments in relationship to the time lines of the data request.

Pre Research Information Access Requirements

All requests for use of data for research from PeriLink^{AB} must be submitted in writing using the AHS Research Agreement template. See Appendix "A" data request forms.

Request Approval Process

The request process will facilitate a single point of contact for stakeholders making requests for use of data in the custody of APHP.

The **APHP Information Management Coordinator** and / or analysts will review requests. The purpose of this review would be to ensure that the requester's question is fully understood, that the data are available and that the request is appropriate. Requests are addressed in the order in which they are received unless there are extenuating circumstances.

The **Data Process Working Group** of the **Information Management Standing Committee** will review data requests for research. The purpose of this review would be to ensure that the request is understood, and that the request complies with data privacy and confidentiality policies of the AHS and APHP. A quorum of 3, excluding the I.M. Coordinator, is required to approve the request. Every effort will be made to present the request for review within two weeks of APHP receiving the request. Requesters of data for research must provide APHP with a copy of the research proposal and evidence of approval by a recognized research ethics board namely, 1) Alberta Cancer Board – Research Ethics Committee, 2) College of Physicians and Surgeons of Alberta – Research Ethics Review Committee, 3) Alberta Heritage Foundation for Medical Research – Community Health Ethics Research Review Committee (also known as Community Research Ethics Board of Alberta), 4) University of Alberta – Health Research Ethics Board, 5) University of Calgary – Conjoint Health Research Ethics Board, 6) University of Lethbridge – Human Subject Research Committee. The proposal will be held in confidence by APHP and the working group members. One copy of the proposal and ethics letter will be retained by APHP. Any copies of the proposal that are

produced for working group members during the review process will be destroyed. Information shall only be disclosed for research purposes in compliance with HIA. Individual Health Care Provider information will not be disclosed for research without explicit consent of the Health Care Provider.

- In any publication or presentation, the users of the data shall acknowledge the APHP and its data sources.
- APHP will reserve the right to request a delay of publication, the request for delay and rationale will be identified at the time of approval of the request.

Monitoring Data Requests

- The Alberta Perinatal Health Program keeps a copy of all data requests and a log of data released
- Research studies requesting client specific data have a duty to comply with the APHP guidelines and conditions as outlined on the APHP Data Use and Disclosure Document (Appendix B), namely;
 1. To comply with the Health Information Act and regulations made under the Act including but not limited to Sections 48 to 56.
 2. Client confidentiality and identity will be protected. Information that has the potential to identify an individual, hospital or physician can never be reported or published.
 3. Data provided through this request will be used only for the research study for which it was approved. A second data request / approval is required if secondary analysis is proposed.
 4. Data provided will be used by the undersigned applicant only unless otherwise stated in the request.
 5. The data must be used appropriately, have restricted access, be maintained securely. Data will not be shared outside of the study team. Data must be stored on a computer that is protected behind a firewall and must not be stored on portable computers or external drives.
 6. Data must be destroyed at the end of the study unless the researcher has been granted permission by the APHP to keep a copy of the data to meet the requirements for publication. The APHP must be notified in writing when the project has been completed and the data has been destroyed.
 7. The undersigned shall take responsibility for his/her own interpretation of the data. The Alberta Perinatal Health Program will provide the researcher with definitions and limitations of the data upon its release.

8. The Alberta Perinatal Health Program may request to examine any proposed manuscript and has the authority to remove parts considered improper or inappropriate for publication or transmission.
9. Presentations, reports, or publications using data from the Alberta Perinatal Health Program database(s) will acknowledge the program as the source of data. The extent of recognition (co-authorship etc) will be defined at the time the request is granted.
10. If the terms and conditions of this agreement are not met or are contravened, the agreement is cancelled.
11. The researcher(s) must not contact the research subjects to obtain additional information.
12. The APHP has the right to access the researcher's premises to confirm compliance with conditions of this agreement and the Health Information Act.

Reference:

Research and Privacy –

<http://insite.albertahealthservices.ca/8122.asp>

AHS INsite Web Page – Where do I go for Information on Research Agreements?

<http://www.albertahealthservices.ca/8599.asp>

Before disclosing information to a Researcher, the **Information Management and Research Coordinator** will ensure that the following requirements are fulfilled.

Information Repository Elements

The **Information Management and Research Coordinator** in discussions with the Researcher will request a complete list of the data elements being requested by the Researcher. The **Information Management and Research Coordinator** will review the requested information elements to confirm that the elements are available in the repository. The list of data elements that can be provided will be identified in the AHS research agreement.

Research Agreement

Once the **working group** has decided to disclose some or all of the information requested by the Researcher, an AHS Research Agreement will be completed by both parties prior to disclosing the contents of the data elements. The AHS Research Agreement template meets HIA section 54(1) and must be used to ensure compliance to HIA section 54. The **Information Management and Research Coordinator** will retain a copy of the completed, signed AHS research agreement and store it in a secure location.

The Research Agreement will contain the following specific information:

- the names of all the Researchers and research affiliates that will have access to the information,
- a copy of the approved research proposal,
- a copy of the Research Ethics Board (REB) approval letter which may contain conditions,
- the specific information elements if not listed in the research proposal,
- whether additional information is to be collected directly from the research participant,
- whether or not data matching will occur.

The **Information Management and Research Coordinator** will not disclose the contents of any information elements that are not listed in the Research Ethics Board approved research proposal. Requests for additional data elements will not be disclosed until the researcher has submitted an amended research proposal to the Research Ethics Board and received approval from the Research Ethics Board. The **Information Management and Research Coordinator** will attach a copy of the amended research proposal and Research Ethics Board approval to the AHS Research Agreement.

Should the **working group** decide not to disclose some or all of the information to the Researcher, the **Information Management and Research Coordinator** will document his/her rationale for not providing the information.

Reference:

AHS INsite Web page – Where do I go for Information on Research Agreements?

<http://www.albertahealthservices.ca/8599.asp>

Research Information Management Policy 1146

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

Undertaking a Research Agreement – IPO Standard 2012-0005

<http://insite.albertahealthservices.ca/legal-privacy/tms-lp-privacy-standard-research-agreements.pdf>

AHS Research Agreement

<http://insite.albertahealthservices.ca/legal-privacy/tms-lp-ahs-research-agreement.doc>

Research Agreements in Compliance with Health Information Act

<http://insite.albertahealthservices.ca/legal-privacy/tms-lp-memo-research-agreement.pdf>

AHS Research Resources

<http://insite.albertahealthservices.ca/1218.asp>

Clinical Trial Research Agreement

The APHP does not have direct access to patients and therefore does not participate in clinical trials. Clinical Trial Agreements must go through AHS Legal.

Implementing Research Ethics Board Conditions

The **Information Management and Research Coordinator** will review the Research Ethics Board approval letter provided by the researcher and examine it to see if the Research Ethics Board has imposed any conditions (i.e. requires participant consent) on the Researcher. If the letter states the Researcher can request anonymous or de-identified information, then ensure the data elements the Researcher is requesting are non-identifiable. Information & Privacy will be consulted if there is uncertainty. The **Information Management and Research Coordinator** will enforce the applicable conditions.

Introducing Studies and Contacting Patients

Not applicable

Research Participant Consent

While the Research Ethics Board may not require participant consent, the **Information Management and Research Coordinator**, in consultation with AHS Research and others as appropriate, may impose the condition on the Researcher which requires consent. In this situation, the contents of the information elements requested by the Researcher for each participant will not be disclosed until written consent is received by the **Information Management and Research Coordinator** from the participant. Should the participant rescind their consent in writing at any time, the **Information Management and Research Coordinator** will not disclose any further information about the participant to the Researcher.

Information Access Restrictions

Information access restrictions limit the access to the contents of the information requested by the researcher. The **Information Management and Research Coordinator or designate** will provide the information to the researcher in an agreed upon format. Direct access to PeriLink^{AB} by a researcher is not permitted.

- All requests for information from the APHP database must be in writing; submitted either on the AHS Research Agreement template for research, or on the AHS / APHP Data Request form for aggregate compiled reports . See Appendix A and Appendix C for data request forms.
- Requests for an aggregate AHS / APHP Compiled Report will be provided at the discretion of **the Information Management and Research Coordinator**
- Written requests for aggregate data must describe in sufficient detail: the purpose of the inquiry, specific variables required, and the intended use for the information.
- Only data elements approved by the Health Research Board will be disclosed

- A fee to perform the request may be implemented. The fee is on a cost recovery basis. A written quote of the estimated cost to complete the request is given at the time that approval of the request is granted.
- Data requests can be denied.
- Paper records in the control of APHP are transitory records. The **Information Management and Research Coordinator** will re-direct any requests for paper records to the original source of the paper document i.e. facility where the birth occurred.

De-Identified AHS Compiled Report

Allowed. The *Health Information Act* permits disclosure but at the discretion of the **Information Management and Research Coordinator**.

1. Personally Identifiable AHS Compiled Report

Allowed. Must be provided by the **Information Management and Research Coordinator**, or designate if full or partial access to the Repository is denied.

APHP will include the following information for data or reports provided in response to a data request:

- a. Data definitions
- b. Source of data
- c. Identification of any limitations of the data.
- d. Formulas used for data manipulation (percentage calculations, averages, etc.)

Information Repository Access

Not applicable

Computer-Based Repository Access

Not applicable

Paper-Based Repository Access

Not applicable

Recommended Researcher Access to Repositories

The following sections briefly describe Alberta Health Services researcher access permissions to repositories.

2. No Information Repository Access

Default. For all repositories that do not contain information approved by the Research Ethics Board in the research proposal.

3. Aggregate AHS Compiled Report

Allowed. The Health Information Act permits disclosure but at the discretion of the **Information Management and Research Coordinator, or designate**.

4. De-Identified AHS Compiled Report

Allowed. The *Health Information Act* permits disclosure but at the discretion of the **Information Management and Research Coordinator or designate**.

5. Personally Identifiable AHS Compiled Report

Allowed. Must be provided by the **Information Management and Research Coordinator or designate** if full or partial access to the Repository is denied.

6. Partial Information Repository Access (subset)

Not allowed.

7. Full Information Repository Access

Not allowed.

Research Information Cost Recovery

Where cost-recovery is necessary, the **Information Management and Research Coordinator** will be responsible for tracking costs. Costs may be incurred from such things as – providing information, data matching, obtaining consent from participants, etc. Fees will be defined in the AHS research agreement. The **Information Management and Research Coordinator** will arrange for the collection of fees for providing the information in compliance with *Health Information Regulation 70/2001*.

Post Research Information Access Requirements

Upon completion of the research project, the **Information Management and Research Coordinator** will ensure that the disclosed data elements provided to the researcher are returned to the **APHP** or disposed of in a secure manner as specified in the Research Agreement.

Reference:

Research Information Management Policy 1146 –
<http://insite.albertahealthservices.ca/Files/cpd-pol-approved-research-info-management.pdf>

5. Requests Regarding Health Information

All requests regarding Health Information are forwarded to **Health Information Management** for processing to ensure that these requests are handled in compliance with the Health Information Act.

Formal Health Information Access Requests

The **Information Management and Research Coordinator** will handle '*Formal Requests*' in consultation with Health Information Management to ensure that these requests are handled in compliance with the *Health Information Act*. Formal requests are those received in writing that reference the *Health Information Act*.

Data received by the APHP for PeriLink^{AB} (i.e. delivery records, lab test results, diagnostic imaging results, etc) are received in a 'condensed' form for the purposes of the Repository from another source.

Requests for access to personal information directly from the individual whose information is being requested, their legal representative, or from AHS Information and Privacy are re-directed to the true source of the information or forwarded to Health Information Management by the Information Management and Research coordinator.

Informal Health Information Requests

Informal requests are those received verbally or in writing that do not reference the *Freedom of Information and Protection of Privacy Act* or the *Health Information Act*. The **Information Management and Research Coordinator** will re-direct informal requests, from individuals, or from an authorized representative of the individual, who wish to view or receive copies of their own health information to the original source of the information or to Health Information Management.

Third Party Requests for Disclosure of Health Information

The **Information Management and Research Coordinator** will re-direct requests from third parties (an individual, custodian, organization or business other than the person that the information is about) for disclosure of health information to the original source of the information or to Health Information Management.

Reference:

AHS FOIP and HIA Access Services –

<http://insite.albertahealthservices.ca/1210.asp>

Consent to Disclose Health Information –

<http://insite.albertahealthservices.ca/frm-18028.pdf>

Request to Access Information under the Freedom of Information & Protection of Privacy Act - <http://insite.albertahealthservices.ca/frm-18028.pdf>

Guidelines for Disclosure of Health Information –

<http://insite.albertahealthservices.ca/legal-privacy/tms-lp-disclosure-guidelines-law-enforcement-specific-guide.pdf>

Collection, Access, Use and Disclosure of Information Policy 1112 –

<http://www.albertahealthservices.ca/Policies/ahs-pol-collection-access-use-disclosure-information.pdf>

Health Information Requests for Correction or Amendment

N/A

Collection and Use of Health Information

The **Information Management and Research Coordinator** is responsible for ensuring that the *Health Information Act* requirements relating to the collection and use of health information are met.

Data is supplied to the APHP by one of four methods:

- 1) directly from paper records i.e. the prenatal record, delivery record, discharge summaries, newborn record, notice of birth etc.
- 2) from a log book record which is transcribed from the province wide delivery record
- 3) by secure electronic transfer or
- 4) by direct data entry at a hospital site.

Facilities that submit their delivery information as paper records submit them to either the north or south office of the Alberta Perinatal Health Program. Data are collated in PeriLink^{AB} for analysis and reporting. This data is the minimum data necessary for APHP to fulfill its mandate.

Once the data has been received at the APHP, it becomes subject to the principles outlined in this document.

Collection of Identifying Information

Personal information collected by the APHP is used for the purpose of internal management, communication with the data source to follow up on missing or erroneous information, for health provider education or investigations or for audit purposes at the request of the facility.

All health and personal information contained in records under the control or custody of the APHP shall be regarded as confidential and available only to authorized users.

Persons who have been granted access to health and personal information are responsible to protect the confidentiality and privacy of the individuals who are the subject of the information, to use the information responsibly and appropriately, and to maintain the integrity and accuracy of the information

Data Validation

The **Information Management and Research Coordinator** is responsible for ensuring every effort is made to ensure accuracy of the data at both the data source and by APHP. Validation is performed on the data to check for errors and inconsistencies in documentation and coding. Facilities may be asked to verify or supply data that appears to be omitted or erroneous. Should the APHP be unable to verify regional data, the data will be coded as "missing".

Data Analysis and Reporting

Data analysis is performed for the purpose of monitoring the health status of mothers and infants throughout Alberta using a population health approach.

Data are available for aggregation and reporting for perinatal events and outcomes at the provincial, regional, and community level that will support:

- Hospital comparisons and benchmarking
- Zone comparisons and benchmarking
- Peer review of clinical practices, processes and outcomes
- Development of strategies to optimize infant and maternal outcomes
- Development of strategies to shape educational strategies
- Population based risk management and strategic planning

Provincial Reports

The APHP is committed to timely reporting and produces a Provincial Perinatal Report annually. The report is produced for AHS / Covenant Health, and designated stakeholders and is not intended for public distribution. The report is used to for reflective practice, quality improvement and program planning.

A multi-disciplinary working group with representatives from across the province contributes to the development of the report.

6. System Access to Repositories and Auditing

This section describes the access management controls that the Information Repository Owner, or designate are responsible to create and administer to ensure that the account privileges are appropriate for the user. This covers the complete life-cycle of user access from when an account is requested until the account is removed.

User Registration for PeriLink^{AB}

The **APHP** has a formal registration process for all individuals requesting access to the information repository. The registration process includes the following activities before access is granted:

- The **Information Management and Research Coordinator** will authorize access to the PeriLink^{AB} and user permissions. The **Information Management and Research Coordinator** will inform the **Manager for the individual for whom access was requested** whether access is granted or not. Should the access authorization be granted to PeriLink^{AB} then the **Information Management and Research Coordinator** will create detailed written instructions on how to determine whether access should be granted.
- The **Information Management and Research Coordinator** will keep a permanent record of the request, authorizing individual(s), and privilege level assigned to the user. The record will also include:
 - a field that indicates the type of account. i.e. AHS staff, student, contractor, or third party / vendor support.
 - A registration expiry date which initiates a process to contact the user and repository owner to determine if the access and privilege level is still required.
- The **Information Management and Research Coordinator** will receive an acknowledgment from the requesting individual that they have read and agree to abide by the conditions of access. Acknowledgement can be obtained through a signed statement or through electronic acceptance where a permanent record of the acceptance can be retained.
- The **Information Management and Research Coordinator** will check for duplicate accounts before creating a new one.

User Identification

The **Information Management and Research Coordinator** will ensure that all individuals are issued a unique user identification and the user registration process must ensure that redundant or multiple IDs are not assigned to the same individual.

The **Information Management and Research Coordinator** will ensure that group or generic IDs are not allowed and are only permitted on an exception basis via approval from IT Security and Compliance.

User Authentication

Password Quality

Users must have valid AHS / Covenant Health network access to login to PeriLink^{AB}. Once access to PeriLink^{AB} is granted and the **Information Management and Research Coordinator** has created an account within PeriLink^{AB}, users login to PeriLink^{AB} using their AHS / Covenant Health password.

The APHP is then able to ensure that passwords meet AHS' minimum password requirements for quality and strength.

Password Confidentiality

The **Information Management and Research Coordinator** will be responsible for reminding all users that have been provided access to the PeriLink^{AB} that they are required to keep all access codes and/or passwords confidential.

Password Lifetime

Once the user has been granted an account within PeriLink^{AB} password management for PeriLink^{AB} is seamless with AHS' password maintenance for lifetime requirements. AHS has an automated authentication management system enforcing the password lifetime requirements. When an individual with an account in PeriLink^{AB} updates their AHS password it is automatically updated for logon to PeriLink^{AB}.

New, Temporary and Default Passwords

AHS ensures that all passwords meet the following criteria:

- passwords must meet the password composition requirements as described above.
- user IDs and passwords must be communicated to the end user in a secure manner and through the use of separate communications channels.
- users must be forced to change the password upon initial logon.
- user accounts where new or temporary passwords have been issued must be disabled if the account has not been activated within seven days.
- temporary passwords are changed immediately following their initial use to gain repository access.

Compromised Password Reset

The **Information Management and Research Coordinator**, upon being informed that a password is suspected of having been compromised or has been compromised, will immediately report the incident to AHS' IT Security and Compliance at –

<http://insite.albertahealthservices.ca/3994.asp>

Reference:

Security and Compliance Security Technologies Standard – Network Authentication Password -

http://insite.albertahealthservices.ca/Files/ITSC-16-00030_Network-Authentication-Password-Standard.pdf

Access to Information (Physical, Electronic, Remote) Policy 1105 -

<http://www.albertahealthservices.ca/Policies/ahs-pol-access-information.pdf>

Review of User Access Rights

All user access rights will be reviewed annually by the **Information Management and Research Coordinator** to ensure that each user has only the access privileges required to perform job tasks.

User Access Rights Review Process

The **Information Management and Research Coordinator** or designate will review user access rights annually. The review will ensure there are no dormant accounts and that user access rights are appropriate.

Changes to User Access Rights

The **Information Management and Research Coordinator** will ensure that a user's access rights will be reviewed immediately whenever a user's role in AHS changes or when a user's status changes to prevent access creep, inappropriate or excessive access. Changes include:

- the hiring on an individual,
- a user's move to another role or assignment,
- user name change
- termination

The **Information Management and Research Coordinator** will ensure that the user's supervisor immediately reports all changes that affect the user's access rights to the repository.

Dormant Accounts

The **Information Management and Research Coordinator** will ensure that user activity will be reviewed regularly to ensure that dormant accounts are disabled. The period of inactivity that defines a dormant account will be determined by the **Information Management and Research Coordinator** based on the duties of the individual and sensitivity of the information contained within the PeriLink^{AB}. The period of activity defined for this PeriLink^{AB} is 6 months. The **Information Management and Research Coordinator** or designate will contact the owner of the account or the owner's manager to inform them of the pending change in the account.

Reference:

Access to Information (Physical, Electronic, Remote) Policy 1105 -
<http://www.albertahealthservices.ca/Policies/ahs-pol-access-information.pdf>
Information Technology Acceptable Use Policy 1109 –
<http://www.albertahealthservices.ca/Policies/ahs-pol-it-acceptable-use.pdf>

Vendor Access

Not applicable. PeriLink is supported and maintained by Alberta Health Services. No vendor access is anticipated.

Reference:

Contractor Requirements for Security and Privacy of Information and IT Resources Policy 1107-

<http://www.albertahealthservices.ca/Policies/ahs-pol-contractor-requirements.pdf>

Information Security and Privacy Safeguards Policy 1143 -

<http://www.albertahealthservices.ca/Policies/ahs-pol-information-security.pdf>

Access to Information (Physical, Electronic, Remote) Policy 1105 -

<http://www.albertahealthservices.ca/Policies/ahs-pol-access-information.pdf>

Monitoring and Auditing of IT Resources Policy 1144

<http://insite.albertahealthservices.ca/Files/cpd-pol-approved-monitoring-auditing-it-resources.pdf>

CPSM Request Form to obtain vendor Contract -

<http://insite.albertahealthservices.ca/frm-09646.doc>

AHS High Level Security Assessment – contact IT Security and Compliance for details

AHS Application Security Checklist – contact IT Security and Compliance for details

Auditing

(Auditing will be in a format that is readily understood and interpreted.)

Repository Logging Capability

In accordance with the Alberta Electronic Health Record Regulation 6(1) **Information Management and Research Coordinator** will ensure that the repository is capable of logging the following data elements associated with users' access:

- User identification and application identification associated with an access,
- Name of user and application that performs an access,
- Role or job functions of user who performs an access,
- Date and time of access,
- Actions performed by a user during an access, including, without limitation, creating, viewing, editing, printing and deleting information,
- Name of facility or organization at which an access is performed,
- Display screen number or reference,
- Name and personal health number of the individual in respect of whom an access is performed.

The **Senior Manager – AHS IMTS – Application & Information Management Services** has confirmed that a plan is in place to ensure PeriLink^{AB} has the above capabilities by December 2014.

Reference:

Monitoring and Auditing of IT Resources Policy 1144

<http://insite.albertahealthservices.ca/Files/cpd-pol-approved-monitoring-auditing-it-resources.pdf>

Alberta Electronic Health Record (EHR) Regulation –

http://www.qp.alberta.ca/documents/Regs/2010_118.pdf

Audit Process

The **Information Management and Research Coordinator** will ensure random proactive audits are done quarterly. Audit triggers will include updates to records from a previous time frame or where the birth event occurred at a different facility than the individual works, numerous access attempts, etc. Any suspected privacy breaches will be forwarded to Information & Privacy for investigation.

AHS Internal and External Audits

The **Information Management and Research Coordinator** will ensure that all staff cooperate with all internal or external audits of the repository and comply with all requests for information regarding the repository. Audit requests that require the disclosure of personally identifiable information will be reviewed with the Information and Privacy Office prior to disclosure.

7. Privacy Breaches

The **Information Management and Research Coordinator** will immediately notify the Information & Privacy Office for investigation of breaches of security or violations and will work collaboratively in follow up to the breach, as appropriate to the incident.

Information & Privacy Home Page - <http://insite.albertahealthservices.ca/1189.asp>

Breach Investigation - <http://insite.albertahealthservices.ca/1212.asp>

For a brief tutorial on how to report privacy incidents, please view the [Reporting Privacy Incidents](#) video.

Inappropriate Access to Records

The **Information Management and Research Coordinator** will review access logs on a **quarterly** basis to ensure that AHS affiliates are not viewing records without authorization. All entries in the logs that are suspect are to be reported to the Information & Privacy Office for investigation via the Privacy Intake Line at 1-877-476-9874 or via e-mail at privacy@albertahealthservices.ca.

Reference:

Access to Information (Physical, Electronic, Remote) Policy 1105 -

<http://www.albertahealthservices.ca/Policies/ahs-pol-access-information.pdf>

Collection, Access, Use and Disclosure of Information Policy 1112 -

<http://www.albertahealthservices.ca/Policies/ahs-pol-collection-access-use-disclosure-information.pdf>

Information Technology Acceptable Use Policy 1109 -

<http://www.albertahealthservices.ca/Policies/ahs-pol-it-acceptable-use.pdf>

Monitoring and Auditing of IT Resources Policy 1144 -

<http://insite.albertahealthservices.ca/Files/cpd-pol-approved-monitoring-auditing-it-resources.pdf>

Information Security and Privacy Safeguards Policy 1143 -

<http://www.albertahealthservices.ca/Policies/ahs-pol-information-security.pdf>

Contractor Requirements for Security and Privacy of Information and IT Resources Policy 1107-

<http://www.albertahealthservices.ca/Policies/ahs-pol-contractor-requirements.pdf>

Breach Discovery

The **Information Management and Research Coordinator**, or designate, upon notification or discovery of a privacy breach involving their repository will:

- take immediate steps to prevent any further privacy breaches
- contact the Information and Privacy Office via the Privacy Intake Line at 1-877-476-9874 or via e-mail at privacy@albertahealthservices.ca and complete the Notification of Privacy Breach Form <http://insite.albertahealthservices.ca/frm-09579.doc> reporting the privacy breach, including a complete list of:
 - the names of individuals whose information was breached and the type of personal information that was breached
 - document a list of all AHS affiliates who were involved in the breach or were involved in containing the breach
 - document where or to whom the personal/health information was disclosed
- attempt to recover the disclosed information by arranging to have it returned to the **Information Management and Research Coordinator** If the information cannot be returned then the **Information Management and Research Coordinator** will ensure the information has been destroyed and that no copies of the information were made.
- If the incident involves laptops, memory sticks, phones or other electronic devices, contact AHS Information Technology as well. They can be reached through your local [IT Service Desk](#).

Privacy Breaches Involving Electronic Repositories

In addition to the actions described above, the **Information Management and Research Coordinator**, or designate, will immediately request or retain a complete copy of the user access logs from the time the privacy breach occurred through to the time the breach was contained. The **Information Management and Research Coordinator** will contact both the Information & Privacy Office and IT Security and Compliance at – privacy@albertahealthservices.ca and securityincident@albertahealthservice.ca

Reference:

Mitigating Risks of Lost or Stolen Records –
<http://insite.albertahealthservices.ca/4413.asp>
Information Security and Privacy Safeguards Policy 1143 -
<http://www.albertahealthservices.ca/Policies/ahs-pol-information-security.pdf>
Monitoring and Auditing of IT Resources Policy 1144 -
<http://insite.albertahealthservices.ca/Files/cpd-pol-approved-monitoring-auditing-it-resources.pdf>

Breach Investigation

The **Information Management and Research Coordinator** or designate, and staff, will cooperate fully with the Information and Privacy Office regarding all privacy breach investigations and provide any information requested by the investigator.

Reference:

Delegation of Authority and Responsibilities for Compliance with FOIPP and the HIA Policy 1108 -
<http://www.albertahealthservices.ca/Policies/ahs-pol-doa-foipp-hia.pdf>
Information Security and Privacy Safeguards Policy 1143 –
<http://www.albertahealthservices.ca/Policies/ahs-pol-information-security.pdf>

Post Breach Recommendations

The **Information Management and Research Coordinator**, or designate, will, as soon as practical, implement all of the recommendations documented in the privacy breach report issued by the Information & Privacy Office investigator upon completion of the investigation into the privacy breach.

Reference:

Delegation of Authority and Responsibilities for Compliance with FOIPP and the HIA Policy 1108 - <http://www.albertahealthservices.ca/Policies/ahs-pol-doa-foipp-hia.pdf>
Information Security and Privacy Safeguards Policy 1143 -
<http://www.albertahealthservices.ca/Policies/ahs-pol-information-security.pdf>

8. Business Continuity Plans

The **Information Management and Research Coordinator**, or designate, will work with IT to ensure a Business Continuity Plan (BCP) has been implemented to ensure the continued availability of information contained within the repository following a disruption or interruption.

The **Information Management and Research Coordinator** will ensure that the BCP plan is functional and current by testing that plan on a bi-annual basis.

AHS Information Technology ensures PeriLink^{AB} is backed up on a regular basis. In the event of damage, loss or disruption, data will be restored to ensure confidentiality integrity and timely resumption of services.

There are 3 regularly scheduled back up procedures for PeriLink^{AB}:

1. Full database back up: runs at 1:00 am every Saturday.
2. Database differential back up: runs at 12:05 am daily.
3. Transaction log back up: runs every hour starting from 12:30 am daily.

PeriLink^{AB} serves as a secondary use of information; the data is not used in the provision of clinical care. Should PeriLink^{AB} be unavailable due to a disruption or interruption there would be a backlog in data entry which is an inconvenience and adds to future workload but could be tolerated for a number of days.

Reference:

Business Continuity Planning for IT Resources Policy 1140 -
<http://insite.albertahealthservices.ca/Files/cpd-pol-approved-business-continuity-planningit-it-resources.pdf>

Electronic Repositories

The **Senior Manager – AHS IMTS – Application & Information Management Services** will ensure that electronic copies of the information repository created as part of the BCP are encrypted prior to storage.

As part of the bi-annual BCP test, the **Senior Manager – AHS IMTS – Application & Information Management Services** will confirm that the information contained in back up media is recoverable and accurate.

Reference:

Business Continuity Planning for IT Resources Policy 1140 -
<http://insite.albertahealthservices.ca/Files/cpd-pol-approved-business-continuity-planningit-it-resources.pdf>
Access to Information (Physical, Electronic, Remote) Policy 1105 -
<http://www.albertahealthservices.ca/Policies/ahs-pol-access-information.pdf>

9. Records Management

AHS Records Management Home Page – INsite

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

Classification and Retention of Records

The **Information Management and Research Coordinator** is responsible for ensuring that retention requirements for data are kept current with the AHS Retention Schedule.

PeriLink^{AB} records are classified as '**Confidential**' as it contains personal information and health information. This information is protected and managed in accordance with all related AHS policies. These records fall under **Classification Numbers 0350 and 1550**.

Paper records which are transitory in nature will be retained for a maximum of one year.

Reference:

Information Classification Policy 1142 –

<http://insite.albertahealthservices.ca/Files/cpd-pol-approved-informationclassification.pdf>

Collection, Access, Use and Disclosure of Information Policy 1112 –

<http://www.albertahealthservices.ca/Policies/ahs-pol-collection-access-use-disclosure-information.pdf>

Records Management Policy 1133 -

<http://www.albertahealthservices.ca/Policies/ahs-pol-records-management.pdf>

Records Retention Schedule - Procedure 1133-01-

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

Contractor Requirements for Security and Privacy of Information and Information Technology Resources Policy 1107 –

<http://www.albertahealthservices.ca/Policies/ahs-pol-contractor-requirements.pdf>

Disposition of Records

The **Information Management and Research Coordinator**, or designate, ensure that electronic data collected by the Alberta Perinatal Health Program and stored in PeriLink^{AB} are securely stored in the database indefinitely.

Disposition of Electronic Records

The **Information Management and Research Coordinator**, or designate, will ensure that transitory electronic records that are disposed are done so in a manner so that the information contained in the record cannot be recovered. The media will be disposed of in accordance with AHS Media Disposal standard.

Disposition of Physical Records

The **Information Management and Research Coordinator** or designate, will ensure that disposition of transitory records received by the Alberta Perinatal Health Program is done in a secure manner such that the information contained in the record cannot be recovered. See Records Destruction Procedure 1133-02.

Reference:

Records Management Policy 1133 -

<http://www.albertahealthservices.ca/Policies/ahs-pol-records-management.pdf> Record

Retention Schedule 1133-01 -

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

Records Destruction Procedure 1133-02 -

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

Transitory Records Procedure 1133-03 - <http://insite.albertahealthservices.ca/Files/cpd-prd-im0703-approved-transitory-records.pdf>

E-Discovery and Legal Holds

The **Information Management and Research coordinator**, or designate, will ensure that any records that are subject to a legal hold or aware of a record about to be placed in a legal hold are protected in such a manner that the record cannot be modified or disposed.

Reference:

Records Management – Legal Hold Procedure 1133-04

<http://insite.albertahealthservices.ca/Files/cpd-prd-im0704-approved-legal-hold.pdf>

10. Other Resources and Links

AHS Resources –

INsite Website - <http://insite.albertahealthservices.ca/1218.asp>

Information & Privacy Home Page - <http://insite.albertahealthservices.ca/1189.asp>

Guide to Alberta's Freedom of Information of Privacy Act (FOIP)

<http://insite.albertahealthservices.ca/legal-privacy/tms-lp-guide-to-FOIP.pdf>

Guide to Alberta's Health Information Act (HIA)

<http://insite.albertahealthservices.ca/legal-privacy/tms-lp-guide-to-HIA.pdf>

Guidelines for the Disclosure of Health Information

<http://insite.albertahealthservices.ca/legal-privacy/tms-lp-disclosure-guidelines-law-enforcement-specific-guide.pdf>

Guidelines for Safeguarding and Securing Information

<http://insite.albertahealthservices.ca/legal-privacy/tms-lp-disclosure-guidelines-law-enforcement-specific-guide.pdf>

[Consent to Collect, Use, and Disclose Photograph, Video and/or Sound Recordings](#)

[Consent to the use of a recording device or camera for Photographs, Video or Sound Recordings for Health Care purpose](#)

Other Links –

Alberta Office of the Information & Privacy Commissioner (OIPC)

<http://www.oipc.ab.ca/pages/home/>

Office of the Privacy Commissioner of Canada

<http://www.priv.gc.ca/>

Alberta Health –

Copies of HIA legislation and other resources

<http://www.health.alberta.ca/about/health-legislation.html>

Alberta Queen's Printer – electronic copies of HIA/FOIP

College of Physicians and Surgeons of Alberta –

<http://www.cpsa.ab.ca/>

11. Definitions

AHS Information Repository Owner

The **Information Repository Owner** controls a specific repository and is responsible for defining the procedures and controls for accessing, storing, security, privacy, and disposition of the information in the repository. This includes ensuring that the procedures and controls meet the privacy requirements set forth by the Custodian including the preparation and submission of a PIA to the Office of the Information and Privacy Commissioner of Alberta. The Information Repository Owner is generally defined as the group or department that financed the creation and ongoing support of a repository.

The Health Information Repository Owner can delegate the management of the repository but cannot delegate responsibility for the security and privacy of the information in a repository. In some situations the Information Repository Owner can also be the Information Repository Manager which simplifies the two roles.

AHS Information Repository Manager

The **Information Repository Manager** manages the repository on behalf of the Information Repository Owner. As part of the management it could include implementing access controls to the information based on the policies, procedures, and rules set forth by the Information Repository Owner.

For electronic information repositories the Information Repository Manager is commonly the Information Technology (IT) department. IT management of electronic information repositories would normally include the support of the computer hardware, operating systems, applications, and databases that make up a repository.

For paper based information repositories, the Information Repository Owner tends to also be the Information Repository Manager. This is especially true in small clinics. In larger institutions the paper information repository may contract a records management group to perform all or part of the repository management function. In this situation the records management group is considered to be an Information Repository Manager of that specific repository.

Business Continuity Plans

AHS business continuity plans ensure timely delivery or resumption of critical IT resources to the required level following an interruption to or failure of, at minimum, essential services. A business continuity plan addresses the confidentiality, integrity and availability of the information.

Privacy Breach

A privacy breach occurs when there is an unauthorized collection, use, disclosure, access to, or disposal of personal or health information. It includes failure to comply with AHS policies, or HIA or FOIPPA, concerning our duty to protect the information we hold. Information may be in various formats (e.g. paper, audio recordings, microfiche, and verbal disclosures/conversations, electronic and photographic) and types of information may include that of AHS:

- patients (e.g. name, date of birth, health care number, diagnosis, treatment)
- employees (e.g. employee number, home address, personnel file)
- administrative documents which may be confidential (e.g. draft business proposals, system security diagrams) or may contain personally identifiable information (e.g. reports of employee sick time or patient self-pay invoicing).

13. Attachments

Appendix A – AHS Research Agreement
Appendix B – APHP Data Use & Disclosure
Appendix C – APHP Data Request Form

Appendix "A" AHS Research Agreement



Research Agreement

between

Alberta Health Services

and

Insert Name of Principal Investigator

(Referred to as "the Researcher")

Regarding

Insert Title of Research Proposal

INTRODUCTION

1. Names of the parties to this agreement:
Insert Name of Principal Investigator
Identify the AHS Repository Owner or Service Provider
2. The Researcher has applied to Alberta Health Services for the disclosure of health information for the research purposes described in the Researcher's proposal.

RESPONSIBILITIES OF THE RESEARCHER

3. The Researcher agrees:
 - a) To comply with the *Health Information Act* and all regulations made under it as well as any applicable federal legislation governing privacy, confidentiality and protection of patient information. *HIA section 54(1)(a)(i)*
 - b) To comply with any conditions imposed by Alberta Health Services relating to the collection, use, protection, disclosure, return or disposal of the health information. *HIA section 54(1)(a)(ii)*
 - c) To comply with any requirements of Alberta Health Services to provide safeguards against the identification, direct or indirect, of an individual who is the subject of the health information. *HIA section 54(1)(a)(iii)*
 - d) Not to make any attempt to contact an individual who is the subject of the health information to obtain additional identifiable health information unless the individual has provided the custodian with the consent required as part of section

- 55 of the *Health Information Act*. *HIA sections 54(1)(d) and 55*
- e) Not to publish the health information in a form that could reasonably enable the identity of an individual who is the subject of the information to be readily ascertained. *HIA section 54(1)(c)*
 - f) To allow Alberta Health Services to access or inspect the Researcher's premises to confirm that the Researcher is complying with the *Health Information Act* and *Health Information Act Regulations*, any imposed conditions on use, protection, disclosure, return or disposal of the information and any requirements related to the provision of security safeguards. *HIA section 54(1)(e)*
 - g) To pay the costs associated with file retrieval, obtaining consents (section 55 of *Health Information Act*), data matching, and any other services provided by Alberta Health Services to the Researcher in connection with the request for disclosure of health information described herein. *HIA sections 54(1)(2) and 55*
 - h) To report to Alberta Health Services any breaches of confidentiality and/or security respecting the information from the records at the facility immediately upon identification of such breaches, and to take steps to both remedy the breach and prevent similar occurrences in the future.
 - i) To securely dispose of or return to Alberta Health Services any personally identifying information as set out in sections 9 and 10 herein.
 - j) To use the research information only for purposes identified in the Researcher's proposal as described in Schedule A. *HIA section 54(1)(b)*
 - k) Not to use or disclose the information for any subsequent or other purposes not identified in Schedule A without the prior written approval of Alberta Health Services, and, if required by the Research Ethics Board or Committee, the consent of the individual who is the subject of the information.
 - l) To notify all individuals on the research team that have access to the health information that they must comply with the *Health Information Act* and regulations and with any conditions imposed by Alberta Health Services, as set out in this Agreement.
 - m) To acknowledge in the publication that Alberta Health Services was one of the sources of information for this study.

RESPONSIBILITIES OF ALBERTA HEALTH SERVICES

- 4. Alberta Health Services agrees to disclose the health information or data in the specific format as outlined in Schedule A and in compliance with any conditions required by the Research Ethics Board or Committee.
- 5. Alberta Health Services shall provide other services to facilitate the research allowed by the Research Ethics Board or Committee and as itemized in Schedule D.
- 6. Alberta Health Services agrees to maintain the research proposal as confidential.

GENERAL PROVISIONS

7. This Agreement may be amended or varied in writing with the mutual agreement of the parties.

TERMINATION OR TRANSFER OF AGREEMENT

8. This Agreement may be terminated by either party at any time subject to the following conditions:
- a) Written notification with up to two weeks notice if appropriate
 - b) All research data collected will be kept by the Researcher and subject to the conditions in this document regarding the safeguarding and disposition of health information.
9. In the event the agreement is breached by Researcher and/or health information is disclosed or used in contravention of the terms and conditions of the agreement or the *Health Information Act* or the regulations, the agreement may be immediately terminated by Alberta Health Services. *HIA section 54(4)*. Alberta Health Services may withdraw the research privileges of the Researcher and will require that all individually identifying health information that has been disclosed for the research purpose be returned to Alberta Health Services.
10. Upon the expiration of the time period for which the Researcher must retain the health information to comply with relevant legislation, policies and procedures, the Researcher must return or dispose of the health information provided by Alberta Health Services and any copies made thereof by the Researcher. Should Alberta Health Services agree to the disposition rather than its return, the researcher shall provide Alberta Health Services with a letter that confirms the date and the means of disposition.
11. The Researcher agrees to obtain authorization from Alberta Health Services prior to the transfer of the agreement to another person. Authorization may be withheld at the discretion of Alberta Health Services. Successors shall be bound by the terms and conditions of this Agreement.

By my signature hereunder, I AGREE to be bound by the terms and conditions herein.

Researcher (Principle Investigator)

Insert Name of Principle Investigator
Name

Signature

YYYY-MM-DD

Date

Alberta Health Services

Identify the AHS Repository Owner or Service Provider
Name

Title of AHS Signatory

Title

Signature

Date

SCHEDULE A: COPY OF THE RESEARCH PROPOSAL

Provide a copy of the Researcher's Proposal along with any amendments

SCHEDULE B: COPY OF THE RESEARCH ETHICS BOARD OR COMMITTEE APPROVAL

Provide a copy of the approval letter(s) of the Research Ethics Board or Committee designated in the Designation Regulation under the Health Information Act – to be provided by the Researcher. Also the Researcher shall submit all approved amendments to the Research Proposal.

SCHEDULE C: LIST OF REQUIRED DATA ELEMENTS

SCHEDULE D: ADDITIONAL CONDITIONS

This is an optional schedule where AHS can request additional detail for the research agreement. Examples include: statement of fees, additional information on security and privacy controls to protect the information including a signed Confidentiality Agreement if the Researcher is provided access to AHS network for this specific research proposal.

Appendix "B" APHP Data Use & Disclosure



Vision: Optimal health for expectant mothers and the infants that are born each year in Alberta

Alberta Perinatal Health Program Data Use & Disclosure:

The Alberta Perinatal Health Program (APHP) is a program within Alberta Health Services. APHP Services are delivered through four integrated functional areas, Leadership and Coordination, Education and Consultation, Quality and Innovation and Information Management and Research. The Information Management and Research team is responsible for overseeing collection and collation of Perinatal data in a provincial data repository; PeriLink^{AB}.

The primary data source is the provincial delivery record filled out at each hospital in Alberta and by Registered Midwives attending home births. The records / data are forwarded to Alberta Perinatal Health Program either in a paper or electronic format.

The APHP supports the use of data in its custody for the purpose of research, with a view to achieving optimal health for mothers and infants in Alberta.

Any facility or individual in Alberta interested in perinatal health may request data from the APHP data repository. Before approval is granted, the APHP will evaluate requests according to security and confidentiality of data, scientific merit, public interest and value, and workload commitments in relationship to the time lines of the data request.

Request Approval Process

The request process will facilitate a single point of contact for stakeholders making requests for use of data in the custody of APHP.

The APHP Information Management Coordinator and / or analysts will review requests to ensure that the requester's question is fully understood, that the data are available and that the request is appropriate and complies with data privacy and confidentiality policies of Alberta Health Services and the APHP. Requests are addressed in the order in which they are received unless there are extenuating circumstances.

The Data Process Working Group of the Information Management Standing Committee will review and approve data requests for research. Once APHP receives the request, every effort will be made to present the request for review within a timely manner. Requesters of data for research must provide APHP with a copy of the research proposal and evidence of approval by a recognized research ethics board. One copy of the proposal and ethics letter will be retained by APHP. Information shall only be disclosed for research purposes in compliance with the Health Information Act (HIA). Individual Health Care Provider information will not be disclosed for research without explicit consent of the Health Care Provider.

- Requests from a member of the public to view their own record(s) will be dealt with according to HIA/FOIPP legislation.
- All requests for information from the APHP database must be in writing.
- Written requests for data must describe in sufficient detail: the purpose of the inquiry, specific variables required, and the intended use for the information.
- Identifiable client data will NOT be disclosed.
- A fee to perform the request may be implemented. The fee is on a cost recovery basis. A written quote of the estimated cost to complete the request is given at the time that approval of the request is granted.
- Data requests can be denied.
- In any publication or presentation, the users of the data shall acknowledge the APHP and its data sources.
- APHP will reserve the right to request a delay of publication, the request for delay and rationale will be identified at the time of approval of the request, or on release of data, or after review of the proposed manuscript.
- All disclosures of identifiable information shall be in accordance with the Health Information Act (HIA).



Vision: Optimal health for expectant mothers and the infants that are born each year in Alberta

Request for Access to Alberta Perinatal Health Program Data

Name and Title of the Individual Making the Request: _____

Organization the Requesting Individual Represents: _____

Telephone Number: _____ Email Address: _____

Specific Variables Required: _____

Time Frame - Year(s) of Data Required: _____

Purpose of Inquiry: _____

Intended Use of the Information: _____

Will the project for which the data are required be funded? Yes No Application Pending

Date when the Data are Required: _____

Appendix "C" APHP Data Request Form



Vision: Optimal health for expectant mothers and the infants that are born each year in Alberta

Request for Data from the Alberta Perinatal Health Program

Name and Title of the Individual Making the Request: _____

Organization the Requesting Individual Represents: _____

Telephone Number: _____ Email Address: _____

Specific Information / Variables Required: _____

Time Frames being Requested: _____

Purpose of Inquiry: _____

Intended Use of the Information: _____

Date when the Data are Required: _____

I hereby agree to the following conditions:

1. To comply with the Health Information Act and regulations made under the Act.
2. Data provided through this request will be used only for the purpose for which it was approved.
3. Data provided will be used by the undersigned applicant only, unless otherwise stated in the request.
4. The data must be used for the purpose stated and be reported in the appropriate context in which it was provided.
5. The undersigned shall take responsibility for his/her own interpretation of the data. The Alberta Perinatal Health Program will provide the undersigned with definitions and limitations of the data upon its release.
6. The Alberta Perinatal Health Program will be acknowledged as the source of data.
7. There may be a charge for the data. This is dependent upon the time frame in which the data is required, the amount of time required to retrieve the data, the amount of data requested, etc. You will be notified if a charge is applicable.

Date

Applicant Signature

South Office
Suite 310, South Tower, Foothills Medical Centre
1403 – 29 Street NW, Calgary, AB T2N 2T9
Tel: (403) 944-1242 Fax: (403) 944-1243
www.aphp.ca

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