



Information Management Guidelines

October 2007

***OPTIMAL HEALTH FOR MOTHERS AND THE INFANTS WHO ARE
BORN EACH YEAR IN ALBERTA***

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INTRODUCTION

Purpose:

The purpose of this document is to outline the Alberta Perinatal Health Program's policies and procedures for collection, use and disclosure of health information as required by relevant privacy legislation (Health Information Act, Freedom of Information and Protection of Privacy Act etc.).

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 that may come in contact with health information. Any facility or individual 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.

This document will be reviewed regularly and updated as needed.

Background:

On July 1, 2004 the Alberta Perinatal Health Program (APHP) was formed. The APHP is being delivered through a Tripartite Partnership between Capital Health, Calgary Health Region and the Alberta Medical Association.

Originally, there were three perinatal programs in Alberta responsible for the collection and reporting of perinatal data: the Committee on Reproductive Care of the Alberta Medical Association, the Southern Alberta Perinatal Outreach Program and the Northern & Central Alberta Perinatal Outreach Program. With the establishment of the Alberta Perinatal Health Program, the functions of these three programs are consolidated under the APHP, and new expanded mandates have been defined.

Alberta Perinatal Health Program – Information Management and Research Core Business:

The core business function of Information Management within the APHP has been identified as: *Collaborate with health regions, health professionals, Alberta Health & Wellness, & other stakeholders on activities to monitor and assess the health status of mothers & infants in Alberta*

Key program activities identified for the information management and research function within the APHP have been identified as:

- Collection of Provincial perinatal data to support the mandate of the APHP
- Analysis and interpretation of data to provide information to Health Regions and those providing perinatal services
- Support perinatal research
- Expansion of data collection to meet the full scope of the APHP - preconception to one year of life.

Definitions:

Alberta Perinatal Health Program (APHP) – The APHP is a provincial perinatal program, established July 1, 2004, with a vision to achieve optimal health for mothers and infants that are born each year in Alberta. The Program is grant funded by Alberta Health and Wellness with a mission to promote maternal health, positive birth outcomes and healthy infancy by providing provincial leadership and enhanced support to health regions, health professionals, Alberta Health and Wellness and other stakeholders. The scope of the APHP is the period from preconception up to the first year of life.

Information Management and Research Coordinator - the person responsible for managing the day-to-day operations of the Information Management and Research function within the APHP. The Information Management and Research Coordinator is the designated privacy officer for the APHP

Facilities – Care Providers, administrators, and providers of health information are considered part of a unit that provides perinatal care. For the purposes of this document, these units are referred to as facilities.

Client - The person (mother or baby) from which perinatal data are collected and stored in the APHP database.

Data Source – Facilities that provide perinatal data to the APHP.

APHP Perinatal Database - is a collation of data collected on women and their infants delivered in Alberta – regardless of the outcome of the delivery.

Information Management Standing Committee – a committee of individuals selected from a variety of areas of expertise - physicians, researchers, information technology, nursing, epidemiology, etc. who provide advise and guidance to the information management team of the APHP.

General Principles:

- The APHP is the steward for the perinatal database and is responsible and accountable for the database.
- The APHP agrees to collect and store the data in a manner that ensures data integrity, security and confidentiality by providing back-ups, password protection, and restricted access to the database. Facility-specific policies will be consistent with the principles of this document.
- The APHP is in compliance with current provincial legislation and policies for health information pertaining to security, confidentiality, and professional codes of practice.
- The facilities in which care is provided to mothers and babies are the stewards of the data collected in that facility.
- The APHP uses a multifaceted approach that addresses individual and population perinatal health issues.

- The APHP manages information to proactively identify, prioritize and address perinatal health issues with an emphasis on quality improvement, advocacy, evidence-based optimal practice, education and information.
- The APHP is committed to timely and meaningful reporting to the program’s Health Region stakeholders / partners.
- 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.
- The APHP uses data in its custody to support provincial and regional strategic planning.

DATA MANAGEMENT

Health information in the custody of the Alberta Perinatal Health Program is collected, stored, used and disclosed in accordance with privacy legislation established by the Government of Alberta.

Authority of APHP to Collect Health Information

Management and responsibility for the APHP [formerly the Southern Alberta Perinatal Outreach Program, the Northern Alberta Perinatal Outreach Program and the Committee on Reproductive Care of The Alberta Medical Association (C.M.A. Alberta Division) (the AMA)] was assumed by the Tripartite Partnership July 1, 2004 with a mandate for four core functions: Leadership & Coordination; Education & Consultation; Quality Improvement & Information Management. The Tripartite Partnership, comprised of the AMA, Capital Health, and Calgary Health Region, was established by a Memorandum of Understanding (MOU) dated June 22, 2004. The MOU outlines the purpose, proposed structure and general responsibilities within the Tripartite Partnership. Items 13 and 14 of the MOU are specific to the information management function of the partnership and state:

13. It is acknowledged that the CHR and CH are “custodians” within the meaning of the *Health Information Act*. For the purposes of the Tripartite Partnership, AMA is appointed an affiliate of CHR and CH in relation to the services provided by the AMA under the APHP and is permitted to collect, use and disclose health information the AMA requires for the purpose of providing those services.

14. The Tripartite Partnership and the members thereof shall adhere to and comply with the *Health Information Act*, including, without limitation section 35 thereof.

The APHP works in a reciprocal relationship with Health Regions. The relationship is formalized through a Partnership Accord. Each Health Region appoints the AMA, Capital Health and Calgary Health Region as an “affiliate”, as described in the HIA. The Tripartite Partnership will collect, store, use, and disclose data in compliance with privacy legislation and according to established protocols. Analysis and interpretation of data by the Tripartite Partnership will, among other things, support development of strategies to optimize infant & maternal health outcomes through education, quality improvement & research.

Duties of APHP as a Custodian as identified in the Health Information Act (HIA)

The APHP has a duty to comply with all privacy legislation and regulations. Including but not limited to Sections 60 – 67 of the HIA, which specifies the following duties of custodians:

- i) Protect confidentiality and privacy of health information under its control.
- ii) Protect the confidentiality of health information that is stored or used or disclosed to a jurisdiction outside of Alberta.
- iii) Protect against a threat or hazard to the security or integrity or loss of the health information.
- iv) Protect against unauthorized use, disclosure or modification of the health information.
- v) Ensure compliance with the Act by custodians and affiliates.
- vi) Establish safeguards for the proper disposal of records to prevent unauthorized use or disclosure of health information.
- vii) Make a reasonable effort to ensure data is accurate and complete before using or disclosing information.
- viii) Identify affiliates of the program that may have access to the health information.
- ix) Establish policies and procedures that facilitate implementation of the Act
- x) Submit a privacy impact assessment to the Commissioner before implementing any new practice or system or any proposed change to existing practices and systems.
- xi) Sign confidentiality agreements with contract employees that may have access to the health information and ensure their compliance with the Act

Data Submission

Each facility identifies who will be responsible for collection and transfer of data to the APHP office(s). Data are supplied to the APHP one of three 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 or 3) by secure electronic transfer. The facilities submit their delivery information to either the north or south office of the Alberta Perinatal Health Program. Data collected by the data sources and received by the APHP, is collated in the provincial database. Such 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. Data are collected from approximately 77 facilities throughout Alberta for approximately 45,000 births and approximately 400 deaths each year.

Data Validation

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

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
- Regional 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 primary purpose of the report is to provide information to health regions and those working in facilities delivering perinatal services. The report is produced for the facilities, health regions and their designated representatives and is not intended for public distribution. Dissemination of the report is directly to representatives of each facility, designated by the health region.

The report is derived from data from the provincial delivery record and where relevant, the associated mortality data. The report provides health regions with comparative information upon which to review practices in their health region. Each health region is provided comparative information that may be then used to support decisions and program planning.

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

Ad Hoc Reports

Reports are produced in response to specific requests for data/information. Facilities can make a request to the APHP to have a report prepared for them.

All reports produced by APHP either by specific request or as standard reports are produced for the health care audience in confidence.

Data Security:

- Security awareness training is mandatory for all APHP staff involved handling health or personal information and is provided to APHP staff through Capital Health or Calgary Health Region.
- Patient names or other information that may identify an individual are removed from the paper records forwarded to the APHP prior to archiving.

- Access to the database is password protected and resides on a dedicated APHP server within the Calgary Health Region
- Support staff responsible for data entry, health records analysts, information management and quality assurance program coordinators, and clinical research associate(s) only are permitted access to the data.
- Computer disks, logbooks, and any parts of a client's chart in the custody of APHP are stored in a locked cabinet.
- The database is backed up on a daily basis.
- Any information APHP sends or receives electronically shall be securely transmitted.
- Transmission of documents by facsimile shall be in accordance with the "Guidelines on Facsimile Transmission" issued by the Office of the Information and Privacy Commissioner
- Individual identifying information shall not be transmitted by email
- These data security standards shall be described in greater detail in a PIA.

Breach Response

APHP staff will report breaches of security or violations as soon as possible to the Information Management and Research Coordinator. The APHP Coordinator will immediately notify the Information and Privacy Coordinator at the appropriate Health Region and will work collaboratively with the Health Regions in follow up to the breach as appropriate to the incident. Investigations will summarize the event and suggest remedial action in accordance with procedures.

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 Use & Disclosure:

The Partnership Accord signed by all the Health Regions facilitates the opportunity for data sharing and devising comparative reports, and to establish a mechanism to handle requests for data access. An individual identified by the Region acts as a steward for the hospital / Health Region.

Any facility or individual interested in perinatal health may request data from the APHP database(s). 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. Requests for data require different levels of approval according to the degree of confidentiality and sensitivity associated with the request. These categories and the approval process are described below.

Request categories

- A. Requests from facilities that contribute data to the database(s), for their own information
- B. Requests for general aggregate data
- C. Requests that require access to individually identifiable records
- D. Requests that require data matching to other databases. The request could be for access to matched data or compiled information

Responding to Requests for Access and Disclosure

- All requests for information from the APHP database must be in writing. See Appendix A and Appendix B for data request forms.
- Requests from a member of the public to view their own record(s) will be dealt with according regional policies and practices which are compliant with HIA/FOIPP legislation.
- 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.
- Requests by a third party for access to previously generated APHP reports will be transferred to the Health Region where the data originated or for whom the report was originally prepared.
- Data requests can be denied.

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 that fall into category A or B (listed above). 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 and approve data requests that fall into category C or D (listed above) and / or any other requests that the APHP IM team feel appropriate. The purpose of this review would be to ensure that the question is understood, and that the request complies with data privacy and confidentiality policies of the 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.
- All disclosures of identifiable information shall be in accordance with the HIA.

Monitoring Data Requests

- The Alberta Perinatal Health Program keeps a copy of all data requests and a log of data released.
- Research studies requesting Non Identifiable Client Specific Data have a duty to comply with the APHP guidelines and conditions as outlined on the data request form for Research (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 undersigned 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.
 - 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.)

Retention & Disposal of Data:

- Paper copies of provincial delivery records logbooks etc. received at the APHP will be stored in a locked cabinet for 2 years. At the end of 2 years the data will be disposed of in containers or shredders that are designated for the disposal of confidential documents.
- Electronic data received by the APHP, on a disk, is stored in a locked cabinet for 2 years. At end of 2 years the discs are disposed of in containers that are designated for the disposal of confidential information.
- All years of data collected by the APHP are securely stored in the database indefinitely.
- A copy of annual, ad hoc, and statistical reports produced by the APHP will be kept on file at the APHP Offices indefinitely.

References

Canadian Perinatal Regionalization Coalition (1997, Dec.). Canadian Perinatal Surveillance System Data Management Guide. London: Author.

PEI Reproductive Care Program Inc. (1998). PEI Perinatal Database Data Management Policies. Charlottetown: Author.

Reproductive Care Program of Nova Scotia (1998, June). Nova Scotia Atlee Perinatal Database: Data Management Principles. Halifax: Author.

British Columbia Reproductive Care Program, British Columbia Perinatal Database Registry Data Access and Release Policies. British Columbia: Author

Province of Alberta (1997, Oct.). Freedom of Information And Protection of Privacy Act : Freedom of Information and Protection of Privacy Regulation. Edmonton: Queen's Printer.

Province of Alberta (1999, Oct.). Health Information Act : Edmonton: Queen's Printer.

Alberta Medical Association (December 2002). Alberta Medical Association Privacy Policies and Procedures. AMA: Author

Alberta Perinatal Health Program (June 2004); Memorandum of Understanding Tripartite Partnership

Alberta Perinatal Health Program (November 2004), Alberta Perinatal Health Program Business Plan:. Corine Frick Author.

Office of the Information and Privacy Commissioner Guidelines on Facsimile Transmission
Version 2

Calgary Health Region Policy: Protection and Privacy of Health and Personal Information: Calgary Health Region: Author

Capital Health Directive: Health Information Security: Capital Health: Author

Appendix A

Request for Aggregate Information and / or Data from the Alberta Perinatal Health Program

Name and Title of the Individual Making the Request: _____

Organization the requesting individual is representing: _____

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

Appendix B

Request for Access to Alberta Perinatal Health Program Database(s) - Page 1

Name and Title of the Individual Making the Request: _____

Organization the requesting individual is representing: _____

Telephone Number: _____ Email Address _____

Specific Variables Required: _____

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

Purpose of Inquiry: _____

Intended Use of the Information: _____

Health Research Ethics Approval provided Yes Pending

Research Proposal Provided: Yes Pending

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

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 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 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 undersigned 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.

Request for Access to Alberta Perinatal Health Program Database(s) - Page 2

To be completed by the Alberta Perinatal Health Program:

Cost Estimate for the above request is: _____

Approval has been granted to disclose the variables listed on page 1 to the named researcher under the Authority of Sections 53 and 54 of the Health Information Act:

Yes No

Data are to be used solely for the purpose of the project: _____

Date

Signature
Alberta Perinatal Health Program Representative(s)

To be completed by the Applicant after approval has been granted:

I agree with the conditions set out by the Alberta Perinatal Health Program on page 1 as well as the cost estimate on page 2.

Date

Applicant Signature