

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: _____