Message from the Co-Chairs

Real World Evidence (RWE) studies investigate the impact of an intervention or technology on health outcomes and resource utilization in clinical conditions outside of the controlled clinical trial setting. The evidence is generated from routinely collected health data to evaluate the safety, effectiveness, and value of newly introduced or existing health technologies and/or other interventions.

RWE is playing a growing role in technology adoption, as well as health policy and clinical practice decision-making, recognizing some of the limitations of traditional controlled clinical trials. Governments and health service providers are using RWE to improve health outcomes in priority areas, and to monitor the post-market safety and effectiveness of new or existing health technologies and innovations. This information is also being used to support coverage and procurement decisions, as well as to assess return-on-investment of public dollars. Additionally, clinicians are increasingly using this information in the development of clinical guidelines and decision-support tools, and, with quality RWE, technology developers may improve market access over time.

Alberta is a leader in health innovation, and has distinct advantages that make the province attractive to health and life sciences-related activity, including:

- a single health authority and the largest fully integrated health system in Canada;
- Strategic Clinical Networks to drive innovation and its implementation across the health system;
- advanced and comprehensive health information systems and database assets; and
- world leading clinical, methodological, and analytic expertise in universities and research centres.

Given Alberta’s significant potential to contribute RWE to support decision-making, the Universities of Alberta and Calgary, and the Institute of Health Economics, have led the formation of the Alberta RWE Consortium. We are excited that with the formation of this new Consortium we are now poised to build upon our Alberta advantages, and take a greater leadership role in RWE research, nationally and internationally. The Alberta RWE Consortium will help foster cutting-edge health research with industry and other health sector partners interested in real world data applications in Alberta, utilizing the data assets outlined in this directory. The Consortium will also be instrumental in supporting and fostering the availability and accessibility of additional data assets going forward.
About the RWE Consortium

Alberta has one of the largest, most mature, detailed and comprehensive health system data depositories in Canada. As such, Alberta is poised to become a global leader in RWE generation. To realize this potential, the Universities of Alberta and Calgary, and the Institute of Health Economics, have led the formation of the Alberta RWE Consortium. The Consortium leads RWE studies, supported by industry or other health system partners, and has a mandate to support the development of quality RWE generation and utilization.

Key functions of the Consortium include:

• Optimization of Alberta’s RWE studies
• Strengthening the Alberta RWE ecosystem
• Providing world class project support services, including study design, execution, and knowledge sharing
• Identifying and supporting projects that align with provincial health and policy priorities, ensuring relevance to decision-makers
• Convening the best pan-provincial teams for commissioned, large-scale projects that may also have implementation components

Consortium membership includes key Alberta health system stakeholders such as Alberta Innovates, Alberta Health, Alberta Economic Development and Trade, and Alberta Health Services. The Institute of Health Economics serves as the Secretariat for the Consortium, and is the first point of contact for organizations interested in exploring an RWE study in Alberta.

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Website: www.AlbertaRWE.ca/
About the Directory

This Directory has been prepared by the Alberta RWE Consortium to provide interested organizations with an overview of the major data assets within the province. The identified assets are organized into three (3) different categories.

1. **Clinical** (e.g. laboratory investigations, dispensed pharmaceuticals, immunizations)
2. **Populations & Health Resource Utilization** (e.g. provincial client registry, hospital admissions, physician visits)
3. **Oncology** (i.e., administrative and clinical data specific to oncology)

This Directory will be updated regularly as new assets become available or accessible. Some of the assets in this Directory have more limited access and documentation than others. For all potential RWE projects, research teams working under the leadership of the Consortium will conduct a feasibility assessment to confirm data availability and accessibility for specific requirements.

Below is a high-level overview of some of the data assets in Alberta’s health care system.
Alberta has one of the largest, most mature, detailed and comprehensive health system data depositories in Canada. As such, Alberta is poised to become a global leader in real world evidence generation.
Clinical Data Assets

These assets are drawn from clinical information systems (CISs), as well as other databases that include laboratory tests, imaging, pharmaceutical, and vaccination databases.

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Oncology Data Assets

*These assets are uniquely specific to oncology, and contain both clinical and health resource utilization data.*

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Canadian Primary Care Sentinel Surveillance Network - Alberta (CPCSSN AB)

Category: Clinical  Focus Area: Clinical Information System (CIS)
Start Date: 2008  End Date: Present
Refreshes: Bi-Annually (Jun 30/Dec 31)  Custodian: University of Alberta

Description:
CPCSSN is a primary care research initiative—it is the first pan-Canadian multi-disease public and population health surveillance system. The initiative collects health information from electronic medical records in the offices of participating primary care providers (e.g. family physicians). The aim is to improve the quality of care for Canadians suffering from five chronic and mental health conditions (hypertension, osteoarthritis, diabetes, chronic obstructive pulmonary disease [COPD], and depression) and three neurologic conditions (Alzheimer's and related dementias, epilepsy, and Parkinson's disease).

CPCSSN in Alberta consists of data from two practice-based primary care research networks. These can readily be merged as required. The current holdings contain de-identified, standardized data from around 300 family physicians for 300,000 patients.

Community-Based CISs (Electronic Medical Records) (EMR)

Category: Clinical  Focus Area: Clinical Information System (CIS)
Start Date: Varies  End Date: Present
Refreshes: Daily  Custodian: Physicians

Description:
Community-based primary care and specialist physician offices utilize a number of different clinical information systems, generally referred to as Electronic Medical Records (EMRs). The adoption rate is high, approximately 80-85%. A majority of offices use information systems from one vendor: TELUS Health Solutions (there are three different EMRs in the TELUS portfolio).

Other Remarks:
Currently these EMRs do not share data with Alberta Netcare. However, it is anticipated in the future that elements contained in the records will be systematically uploaded to Netcare and be available for research purposes.
Connect Care & Other Hospital CISs

**Category:** Clinical  
**Focus Area:** Clinical Information System (CIS)  
**Start Date:** Varies  
**End Date:** Present  
**Refreshes:** Daily  
**Custodian:** Alberta Health Services (AHS)  

**Description:**
Currently there are a number of different clinical information systems in use within AHS facilities. AHS plans to consolidate these various information systems under a common, unified CIS, called Connect Care. Connect Care is the bridge between information, healthcare teams, patients, and the future.

Through a common provincial clinical information system, Connect Care will enable consistent practices across Alberta and will improve the care we provide for patients and their families. The goal is to unify over 1,300 independent information systems across AHS.

**Other Remarks:**
The implementation of this system is still in progress and being rolled out throughout Alberta. The goal is to become the central shared CIS within Alberta Health Services once integration is complete.

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Diagnostic Imaging (DI)

**Category:** Clinical  
**Focus Area:** Diagnostic Imaging  
**Start Date:** Jan 2011  
**End Date:** Present  
**Refreshes:** Daily (7 days latency)  
**Custodian:** Alberta Health Services (AHS)  

**Description:**
The DI Shared Data Model contains data elements from three different Radiology Information Systems (RISs); Calgary (Cerner Millennium), Edmonton (AGFA RIS), and Meditech (Aspen, Chinook, David Thompson, East Central, Northern Lights, Palliser, and Peace Country) and excludes any non-AHS data. Data is located in a restricted schema and includes all DI interventions and diagnostic tests as per the CPEL Translation Table (Reference Table) as well as a collection of identifiable patient data from each RIS's ADT clinical source system.

**Other Remarks:**
Restricted access to AHS, but may be available at a later date.
Immunization and Adverse Reactions to Immunizations (Imm/ARI)

**Category:** Clinical  
**Focus Area:** Immunization  
**Start Date:** Varies  
**End Date:** Present  
**Refreshes:** Weekly  
**Custodian:** Alberta Health/Alberta Health Services (AHS)

**Description:**
Imm/ARI is the largest collection of province-wide immunization data currently available. It includes information from:

- AHS immunizers in all zones (this includes all publicly funded vaccine and some travel)
- Pharmacist immunizers (this includes influenza vaccine)

**Other Remarks:**
Immunization data for AHS facilities go back 20-50 years, and select pharmacies go back 6-10 years. The Edmonton Zone updates monthly instead of weekly.

Use by researchers is currently limited to Alberta Health-initiated projects. However, more open access is anticipated, and researcher-initiated requests are currently handled on a case-by-case basis.

This dataset is not population-level.

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Consolidated Laboratory Data Repository (CLDR)

**Category:** Clinical  
**Focus Area:** Laboratory  
**Start Date:** Apr 2015  
**End Date:** Present  
**Refreshes:** Daily  
**Custodian:** Alberta Health Services (AHS)

**Description:**
The CLDR has approximately 25 fields that will capture both historical and current data states (e.g. Personal Health Number, date of birth, test names, test codes, and provider sites). This will allow queries to be run on the data, as it existed at a certain point in time, not just the most accurate data. This will allow data pulls, for example, on current or historical data for provider locations patient identifiers, and test name changes.

**Other Remarks:**
Dataset name currently under review and may change.

Restricted access to third-party (non-AHS) procedures. Restricted access to Lab Provincial Data Team during Testing & Data Validation.
Medical Laboratory (General)

**Category:** Clinical  
**Focus Area:** Laboratory  
**Start Date:** Varies  
**End Date:** Varies  
**Refreshes:** Daily (8 days latency)  
**Custodian:** Alberta Health Services (AHS)

**Description:**
The Laboratory Project Release 1 is all AHS general lab tests and includes clinical chemistry, toxicology, hematology, serology, urinalysis, and immunology. Sites to include Meditech, Millennium, Sunquest, and Optimum Lab (previously LabFusion).

**Other Remarks:**
Available from:
- LabFusion: Jan 1, 2009 to Jan 31, 2017 (*Contract Ended)
- Meditech: Jan 1, 2009 to current
- Millennium: Apr 1, 2012 to current
- Sunquest: Apr 1, 2012 to current

Alberta Blue Cross Claims (ABC)

**Category:** Clinical  
**Focus Area:** Pharmaceutical  
**Start Date:** Apr 1994  
**End Date:** Present  
**Refreshes:** Monthly and Annually  
**Custodian:** Alberta Health

**Description:**
ABC provides information on the following types of claims records covered under supplementary health benefit plans and paid by Alberta Blue Cross on behalf of Alberta Health:
- Prescription drug dispensing under supplementary health benefit plans (97% of ABC records)
- Private or semi-private hospital accommodation
- Claims for extended health services, group and non-group benefits, palliative coverage, coverage for seniors, and low-income benefits

**Other Remarks:**
This dataset covers only seniors, their dependents, and persons on assistance.
Pharmaceutical Information Network (PIN)

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<tr>
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<td>Custodian:</td>
<td>Alberta Health/Alberta Health Services (AHS)</td>
</tr>
</tbody>
</table>

**Description:**
The PIN is the central repository of prescription drugs dispensed from community pharmacies. The data is patient identifiable and includes—but is not limited to—data elements such as patient identification data (Unique Lifetime Identifier, date of birth), drug name, drug identification number (DIN), drug dose, quantity dispensed, and number of days supplied. This is a primary dataset for community drug utilization reviews (DUR) for quality improvement, research, and evaluation in AHS.

PIN includes historical data from 2002 to current and is updated on a weekly update schedule. All available reference tables from Alberta Health and the Health Canada Drug Product Database (HCDPD) are also loaded and updated on a regular schedule.

**Other Remarks:**
Cost and benefit payment information is not available, and the reason for the prescription is not captured. Information is on dispensed drugs (i.e. not prescriptions), and in-hospital dispenses are not included. Accuracy and completeness of data improves over time (currently, about 95% of all pharmacists submit records). Although PIN has been in place since 2002, the regulations that mandated data provision were not enacted until 2007. The data are generally seen as being complete enough for research from 2010 forward.
Alberta Perinatal Health Program (APHP)

**Category:** Clinical  
**Focus Area:** Other Clinical Databases  
**Start Date:** 1998  
**End Date:** Present  
**Custodian:** Alberta Health Services (AHS)

**Description:**  
The APHP collects perinatal data for all hospital births and from the Registered Midwives who attend out of hospital births. Data are supplied to the APHP by one of three methods:

1) directly from paper records,  
2) by secure electronic transfer, or  
3) through direct data entry at the facility where the birth occurred.

Provincial data are collated in PeriLinkAB, a comprehensive perinatal repository that supports the Alberta Perinatal Health Program objectives. Analysis and interpretation of the data supports the Alberta Perinatal Health Program, Alberta Health Services, the Health Zones, and other stakeholders in achieving optimal health for expectant mothers and the infants that are born each year in Alberta.

**Other Remarks:**  
Reports are produced in response to specific requests for data/information. A Data Request Form must be completed to access such data.

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Alberta Real Time Syndromic Surveillance Network (ARTSSN)

**Category:** Clinical  
**Focus Area:** Other Clinical Databases  
**Custodian:** Alberta Health Services (AHS)

**Description:**  
ARTSSN is an automated real-time surveillance data repository able to rapidly refresh data that include school absenteeism information, calls about health concerns from Health Link Alberta (HLA); a provincial telephone service for health advice and information, and emergency department visits categorized by standardized chief complaint.
**Communicable Disease Reporting System (CDRS)**

**Category:** Clinical  
**Focus Area:** Other Clinical Databases  
**Custodian:** Alberta Health  

**Description:**
The CDRS is a collection of functional components used in the tracking of communicable diseases. The CDRS consists of three applications to record communicable disease information. The Notifiable Disease Report (NDR) module is populated with notifiable disease data received from regional health authorities and labs.

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**Perinatal**

**Category:** Clinical  
**Focus Area:** Other Clinical Databases  
**Start Date:** 2004  
**End Date:** 2008  
**Custodian:** Alberta Health Services (AHS)  

**Description:**
The Alberta Perinatal data set contains data from all hospital facilities where women gave birth and from Registered Midwives attending out of hospital births in Alberta. It includes information on pregnancy, birth, and mortality. The perinatal project has been prioritized and is slated to be updated in the AHS Data Repository for Reporting (AHSDRR) with data for 2009, 2010 and 2011 in the upcoming months.
### Admission, Discharge, Transfer (ADT)

**Category:** Populations/Health Resource Utilization  
**Focus Area:** Encounters/Procedures  
**Start Date:** Apr 2007  
**End Date:** Present  
**Refreshes:** Daily  
**Custodian:** Alberta Health Services (AHS)

**Description:**
Contains admission, discharge, and transfer for services (inpatient, ambulatory, and seniors) attached to an acute facility. ADT sources systems of Meditech for the following sites: Aspen Regional Health (ARH), Chinook Health Region (CHR), David Thompson Health (DTH), East Central Health (ECH), Peace Country Health (PCH), Palliser Health Region (PHR), and Northern Lights Health (NLH).

### Alberta Continuing Care Information System (ACCIS)

**Category:** Populations/Health Resource Utilization  
**Focus Area:** Encounters/Procedures  
**Start Date:** Jan 2007  
**End Date:** Present  
**Custodian:** Alberta Health Services (AHS)

**Description:**
The ACCIS provides a mechanism for regional reporting of continuing care information to a centralized repository within Alberta Health, and also allows for reporting of continuing care data to two Canadian Institute for Health Information (CIHI) national databases.

Elements include demographics, admission, and discharge information, as well as outcome scales, quality indicators, and resource utilization groupers as outputs from the interRAI assessment instruments.

**Other Remarks:**
Includes Long-Term Care & Community Care (from Apr 1, 2011). The Community Care dataset is currently considered incomplete, with significant volumes of historical data yet to be submitted.
## Alberta Waitlist Registry

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<th>Encounters/Procedures</th>
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</tbody>
</table>

**Description:**

The general public, healthcare practitioners, and the media use the Waitlist Registry. It provides information for healthcare decision-making as well as fact-based answers to public concerns over waitlists. The key business process that the Registry involves is the collection and analysis of waitlist records and related information that Alberta facilities submit to Alberta Health.

## Alberta Wait Times Reporting (AWTR)

<table>
<thead>
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<th>Category:</th>
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<th>Encounters/Procedures</th>
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<tr>
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<td>Custodian:</td>
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</table>

**Description:**
In 2003, Alberta Health & Wellness (AHW) introduced a website which provides information on wait times for surgical and medical procedures. The AWTR provides accurate and current wait times across the province for publicly funded surgeries and selected diagnostic services. The registry shows aggregate non-identifiable data for how many patients are currently waiting for a procedure by hospital and by physician, and the wait time associated to an elective surgery or diagnostic imaging procedure.

The AWTR is the result of one of the recommendations of the Premier’s Advisory Council on Health. The information on the registry will be used to set realistic access targets and proceed with booking services.

Each month, the Extract/Transform/Load (ETL) runs and calculates new wait time information, based on existing data and the new data that has been received during the month.
Inpatient - Discharge Abstract Database (DAD)

Category: Populations/Health Resource Utilization  
Focus Area: Encounters/Procedures

Start Date: Apr 2002  
End Date: Present

Refreshes: Monthly  
Custodian: Alberta Health/Alberta Health Services (AHS)

Description:
The DAD is a database for information on all AHS separations for acute care institutions, including discharges, deaths, sign-outs, and transfers within a fiscal year (April 1 to March 31). The DAD contains information on recipients, services, diagnoses, and procedure interventions for those who have been discharged from a hospital inpatient bed. Over time, the DAD has also been used to capture day surgery procedures, long-term care, rehabilitation, and other data.

Other Remarks:
Updated monthly. However, all information can be corrected or deleted once submitted; caution is recommended when using open year data. Once a fiscal year is closed, data can no longer be modified. Alberta Health typically discloses data from the closed annual files available in the late Fall each year.

National Ambulatory Care Reporting System (NACRS)

Category: Populations/Health Resource Utilization  
Focus Area: Encounters/Procedures

Start Date: Apr 2010  
End Date: Present

Refreshes: Monthly  
Custodian: Alberta Health Services (AHS)

Description:
The NACRS is a facility-based ambulatory care information (same-day surgery, day procedures, emergency room visits, and community rehabilitation program services occurring in publicly-funded facilities). This dataset contains recipient, service, diagnosis, and procedure interventions. Also includes information about providers and derived elements (e.g., groupers).

This system was formerly known as the Alberta Ambulatory Care Reporting System (AACRS).
Practitioner Claims (Fee-For-Service Claims, Supplemental Enhanced Service Event) (SESE)

**Category:** Populations/Health Resource Utilization  
**Focus Area:** Encounters/Procedures  
**Start Date:** Apr 1994  
**End Date:** Present  
**Refreshes:** Weekly  
**Custodian:** Alberta Health

**Description:**  
This dataset consists of processed claims for eligible Albertans and medical reciprocal patients to pay medical doctors and other allied practitioners (optometrists, podiatrists, podiatric surgeons, and dentists) and to track shadow-billed claims. “Eligible Albertans” have lived in Alberta for more than three months and are registered with Alberta Health to receive Alberta Health Care Insurance Plan (AHCIP) benefits.

Elements include:

- Patient information: identifier, demographic information, location
- Provider information: identifier, specialty, role, location, referring provider identifier, discipline
- Service information: health service code, date of service, amount paid (role, trays, time surcharges, total), service units paid and calls claimed, facility, up to three diagnostic codes, shadow billed claims

**Other Remarks:**  
Privacy of providers is highly protected and must be absolutely de-identified prior to disclosure. Data is updated weekly, but accuracy and completeness of claims data improves as time from date of service increases. A six-month payment lag is typically used.

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Population Health

**Category:** Populations/Health Resource Utilization  
**Focus Area:** Patient/Provider Demographics  
**Start Date:** 1994  
**End Date:** Present  
**Refreshes:** As Needed  
**Custodian:** Alberta Health Services (AHS)

**Description:**  
This table contains six data elements of the Patient/Care-Based Funding Population database. These elements contain information about specific populations from 1994 onward. The elements can be linked via postal code to other data sets for further information about that population. Data is derived from the Provincial Registry data using the Alberta Health Population Projections which are updated approximately every three years. The Alberta Health Population Projections were last updated July 2015.
Population Registry

Category: Populations/Health Resource Utilization
Focus Area: Patient/Provider Demographics

Start Date: Apr 1993
End Date: Present

Custodian: Alberta Health

Description:
The Registry contains demographic information for all Albertans with Alberta Health Care Insurance Plan (AHCIP) coverage. It is used as a base for Alberta population counts. Elements include:

• Personal Health Number, date of birth, sex, postal code
• Active coverage, birth, and death indicators as of March 31
• Migration indicators - whether the person has migrated into Alberta or out of Alberta during the fiscal year (no information on where the person came from or went to)
• Indicator for invalid recipient address (e.g. mail returned to Alberta Health)
• Date and reason coverage was cancelled

Other Remarks:
If registrants do not report address changes, etc., the information on file will not be current. Alberta Health uses other data sources to update registration data when a move to another province or death has occurred, even if the person or family does not report the changes.

Provincial Client Registry (PCR)

Category: Populations/Health Resource Utilization
Focus Area: Patient/Provider Demographics

Custodian: Alberta Health

Description:
The PCR is a patient identification system that links diverse sources of demographic person data information within and across health organizations and jurisdictions, and will provide the foundation for a province-wide Electronic Health Record.

The various groups of users include the Health Region and Alberta Cancer Board Registry Integrity Units, the Provincial Registry Integrity Units (Alberta Health), Stakeholder Registration, and Health Information Management business units.

Other Remarks:
While the PCR also provides population data, it is advised to use the Provincial Registry files for demographic information.
**Provincial Provider Registry (PPR)**

**Category:** Populations/Health Resource Utilization  
**Focus Area:** Patient/Provider Demographics  
**Custodian:** Alberta Health

**Description:**
The PPR is a centralized source of key information about health service providers who are members of regulated colleges. It compiles information and reconciles multiple records from different data sources and acts as a source of truth for those that are authorized to access the information.

The regulated colleges supply health service provider data to the PPR database. The data is managed to eliminate duplicates, link records between colleges, and assign a unique identifier—the HSPID. The health service provider data will then be accessible to authorized health service organizations such as Alberta Health Services, and divisions of Alberta Health, such as the Health Workforce Planning Division.

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**Provincial Registry**

**Category:** Populations/Health Resource Utilization  
**Focus Area:** Patient/Provider Demographics  
**Start Date:** Apr 1994  
**End Date:** Present  
**Refreshes:** Annually (3rd Quarter)  
**Custodian:** Alberta Health Services (AHS)

**Description:**
The Provincial Registry table is also referred to as Population Demographics, and is made available by Alberta Health. Data is extracted from the Alberta Health Care Insurance Plan (AHCIP) Registry and provides basic medical and hospital insurance coverage for most Albertans under the Canada Health Act. The number of registrants is used as a proxy for populations of the regional health authorities for the Annual Population Funding Model.
Vital Statistics

<table>
<thead>
<tr>
<th>Category:</th>
<th>Populations/Health Resource Utilization</th>
<th>Focus Area:</th>
<th>Patient/Provider Demographics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Start Date:</td>
<td>Varies</td>
<td>End Date:</td>
<td>Present</td>
</tr>
<tr>
<td>Refreshes:</td>
<td>Annually (fiscal year)</td>
<td>Custodian:</td>
<td>Service Alberta/Alberta Health</td>
</tr>
</tbody>
</table>

**Description:**
Vital Statistics are defined as records dealing with births, stillbirths, and deaths; all events which have to do with an individual’s entrance or departure from life, together with changes in civil status.

**Other Remarks:**
- Birth Registry - Available from: 1983 to Current (December 31, 2015)
- Death Registry - Available from: 2000 to Current (March 31, 2015)
- Stillbirth Registry - Available from: 1983 to Current (December 31, 2015)

Data managed by Service Alberta, and provided to Alberta Health for use. Service Alberta must authorize any disclosure.

Personal Health Numbers are not necessarily available for all years of the data.

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Vital Statistics – Births

<table>
<thead>
<tr>
<th>Category:</th>
<th>Populations/Health Resource Utilization</th>
<th>Focus Area:</th>
<th>Patient/Provider Demographics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Start Date:</td>
<td>Jan 2005</td>
<td>End Date:</td>
<td>Present</td>
</tr>
<tr>
<td>Refreshes:</td>
<td>Annually (fiscal year)</td>
<td>Custodian:</td>
<td>Service Alberta/Alberta Health</td>
</tr>
</tbody>
</table>

**Description:**
All live births delivered within Alberta must be registered with Alberta Vital Statistics. Upon birth, the Notice of a Live Birth or Stillbirth form (PNOB) is completed and forwarded to Alberta Vital Statistics. In addition to the PNOB, the parents/guardians are required to register the birth with Alberta Vital Statistics completing the Registration of Birth form within 10 days of the birth event. This information is then entered into the Alberta Vital Statistics information system and a birth certificate is issued.

Elements include:
- Date of birth, sex, location of birth, hospital identifier
- Kind of birth (e.g. twins), birth order, gestation, birth weight
- Demographic information on the mother

**Other Remarks:**
Service Alberta is the data custodian and must authorize any disclosure.
Vital Statistics – Deaths

**Category:** Populations/Health Resource Utilization  
**Focus Area:** Patient/Provider Demographics

**Start Date:** Jan 1999  
**End Date:** Present  
**Refreshes:** Annually (fiscal year)  
**Custodian:** Service Alberta/Alberta Health

**Description:**
All deaths occurring in Alberta must be registered with Alberta Vital Statistics. Information in the file is derived from the Death Registration form, medical certificate of death, and the medical examiner’s certificate of death (where appropriate). Additional derived variables are added to the file to facilitate queries and analysis of the data.

Elements include:
- Date of death, place of death, hospital identifier
- Cause of death, attendant at time of death, autopsy
- Demographic information including age, sex, residence

**Other Remarks:**
Service Alberta is the data custodian and must authorize any disclosure.

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Canadian Community Health Survey (CCHS)

**Category:** Populations/Health Resource Utilization  
**Focus Area:** Population Health

**Refreshes:** Not Required  
**Custodian:** Alberta Health

**Description:**
The CCHS is a cross-sectional survey that collects information related to health status, health care utilization, and health determinants for the Canadian population. It surveys a large sample of respondents and is designed to provide reliable estimates at the health region level.

CCHS is a cross-sectional survey that collects information related to health status, health care utilization, and health determinants for the Canadian population. CCHS Cycle 2.2 Nutrition is a national health survey that collects information from Canadians about their eating habits and use of vitamin and mineral supplements, as well as other health factors.

**Other Remarks:**
Data is a one-time microdata file. This non-identifiable microdata file contains characteristics pertaining to survey information. This is a licensed product, subject to the terms of the license agreement.

There are restrictions on the use of CCHS for research purposes, placed on Alberta Health. Contact Alberta Health to learn more.

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Canadian Tobacco, Alcohol, and Drugs Survey (CTADS)

**Category:** Populations/Health Resource Utilization  
**Focus Area:** Population Health  
**Refreshes:** Not Required  
**Custodian:** Alberta Health Services (AHS)

**Description:**  
The CTADS is a biennial general population survey of tobacco, alcohol and illicit drug use among Canadians aged 15 years and older. It replaces the Canadian Tobacco Use Monitoring Survey (CTUMS), which was conducted from 1999-2012 and the Canadian Alcohol and Drug Use Monitoring Survey (CADUMS), which was conducted from 2008-2012. The CTADS merged the core tobacco content from CTUMS and the core drug and alcohol content from CADUMS resulting in more efficient data collection and providing a tool to monitor and compare the use of multiple products and substances with addictive properties. The CTADS is conducted by Statistics Canada on behalf of Health Canada.

**Other Remarks:**  
Data is a one-time microdata file. This non-identifiable microdata file contains characteristics pertaining to survey information. This is a licensed product, subject to the terms of the license agreement.

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National Health Population Survey

**Category:** Populations/Health Resource Utilization  
**Focus Area:** Population Health  
**Refreshes:** Not Required  
**Custodian:** Alberta Health

**Description:**  
The Household component is a longitudinal (collecting health information from the same individuals each cycle) survey containing information on the health of the Canadian population and related socio-demographic information.

**Other Remarks:**  
Data is a one-time microdata file. This non-identifiable microdata file contains characteristics pertaining to survey information. This is a licensed product, subject to the terms of the license agreement.
ARIA (Oncology-Specific CIS)

Category: Oncology  Focus Area: Clinical Information System (CIS)
Start Date: 2008  End Date: Present
Refreshes: Daily  Custodian: Alberta Health Services (AHS)

Description:
ARIA is the electronic medical record system for cancer patients in Alberta, managed by Cancer Control Alberta. The system houses chemotherapy, progress notes, referral, and demographic information, as well as pathology data and some diagnostic imaging data.

Other Remarks:
Some pharmacy information is available, but is not complete. Most pharmacy data is available in the Pharmaceutical Information Network (PIN).

Data is planned to be incorporated into Connect Care in the next 5-7 years.

Alberta Cancer Registry (ACR)

Category: Oncology  Focus Area: Registry
Start Date: 1982  End Date: Present
Refreshes: Annually (Spring)  Custodian: Alberta Health Services (AHS)

Description:
The ACR contains information on patients diagnosed or treated in Alberta. Data collected includes: demographic, initial treatment, mortality, and tumour information. The information based on initial diagnosis and treatment within one year after diagnosis. Treatment data focuses on the occurrence of surgery, chemotherapy, or radiotherapy. Data is completed approximately 1.5 to 2 years after diagnosis and contains no details on recurrence. AHS CancerControl also maintains an internal oncology electronic medical record for this patient level treatment data.

Other Remarks:
Data is available from 1945, but due to changes in coding, data is more consistent from 1982 onward. Access must be granted through a request process, managed internally. These require appropriate ethics and supporting documentation to meet legislative requirements and AHS policy/best practice compliance.
Alberta Cancer Research BioBank (ACRB)

**Category:** Oncology  
**Focus Area:** Research

**Custodian:** Alberta Health Services (AHS)

**Description:**  
The ACRB collects biological materials from participants as well as cancer-related clinical data. This data is stored within an AHS-owned and Privacy Impact Assessment (PIA)-approved database. There are data on approximately 26,000 patients, although not all complete.

All samples are annotated with minimal data (name, date of birth, Personal Health Number, diagnosis, cancer type). A subset of cancer types have enhanced annotation, including breast, ovarian, prostate, colorectal, and lung cancer. Enhanced annotation includes demographics, diagnosis, surgical/pathological tumour parameters (e.g. grade, stage, size, hormone receptor status, genetic information, lymph node involvement), treatment, life status.

**Other Remarks:**  
Access must be approved by the AHS Provincial Research Administration Office, by way of a Material Transfer Agreement (MTA). The data comes in part from electronic data releases from Surveillance and Reporting and in part from manual annotation. It is meant for research alone, and while AHS strives for accuracy, it cannot be guaranteed.

The breast cancer data set is the most complete. In many breast cancer cases, recurrence has been determined, but this is an interpretation of the clinical data and is not verified.