

alberta RWE consortium

albertarwe.ca

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alberta health data asset directory

message from the co-chairs

»» Alberta has one of the largest, most mature, detailed, and comprehensive health system data repositories in Canada.

Real world data is derived from a variety of sources, including routinely collected health information, and is used to generate real world evidence (RWE). Alberta boasts world-class health system data repositories, conferring a distinct advantage for the production of high-quality RWE within the province.

RWE is playing an increasingly central role across the health ecosystem. Governments and health service providers are leveraging RWE to enhance health outcomes, and to monitor the post-market safety and effectiveness of new or existing health technologies and innovations. This information is also being used to inform coverage and procurement decisions, facilitate earlier patient access to novel therapies, and aid in the assessment of public dollar return-on-investment. Additionally, clinicians are increasingly using this information in the development of clinical guidelines and decision support tools. Technology developers are using RWE to drive innovation, and meet evidentiary standards set by regulators and health system decision makers.

Alberta is a global 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 that are outlined in this directory;
- ↳ world leading clinical, methodological, and analytic expertise.

Recognizing the need for high-quality RWE and the distinct advantages of the province, the Alberta RWE Consortium was established in 2018, uniting the collective expertise of the Universities of Alberta and Calgary, along with the Institute of Health Economics. The Alberta RWE Consortium fosters cutting edge health research with industry and other health sector partners interested in high-quality RWE generated from a trusted source, and at a pace that is aligned with the demands for economic competitiveness and informed decision making.



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about rwe consortium

>>> we are a trusted source
for health focused real world
evidence queries.

The Alberta RWE Consortium is comprised of an expert pan-provincial research team from the Universities of Alberta and Calgary, along with the Institute of Health Economics.

Experts in analyzing provincial health system data, we specialize in conducting timely health focused RWE research that actively engages funding partners, decision makers, and knowledge users.

We ensure that meaningful evidence is generated from a trusted source that can be used to inform decision making.

Key functions of the Consortium include:

- ↳ engaging funding partners, decision makers, and knowledge users to identify meaningful and relevant research questions
- ↳ conducting high-quality health focused RWE research studies at a pace that is aligned with the demands for economic competitiveness and informed decision making
- ↳ ensuring integrity of results and producing robust evidence to inform decision making
- ↳ strengthening the Alberta RWE ecosystem

Consortium partnerships include long standing relationships with Alberta health system contributors such as Alberta Innovates, Alberta Health, Alberta Jobs, Economy and Trade, and Alberta Health Services.



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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.

Data assets are organized into three (3) different categories.

①

Clinical

i.e. laboratory investigations, dispensed pharmaceuticals, immunizations

②

Populations and Health Resource Utilization

i.e. provincial client registry,
hospital admissions, physician visits

③

Oncology

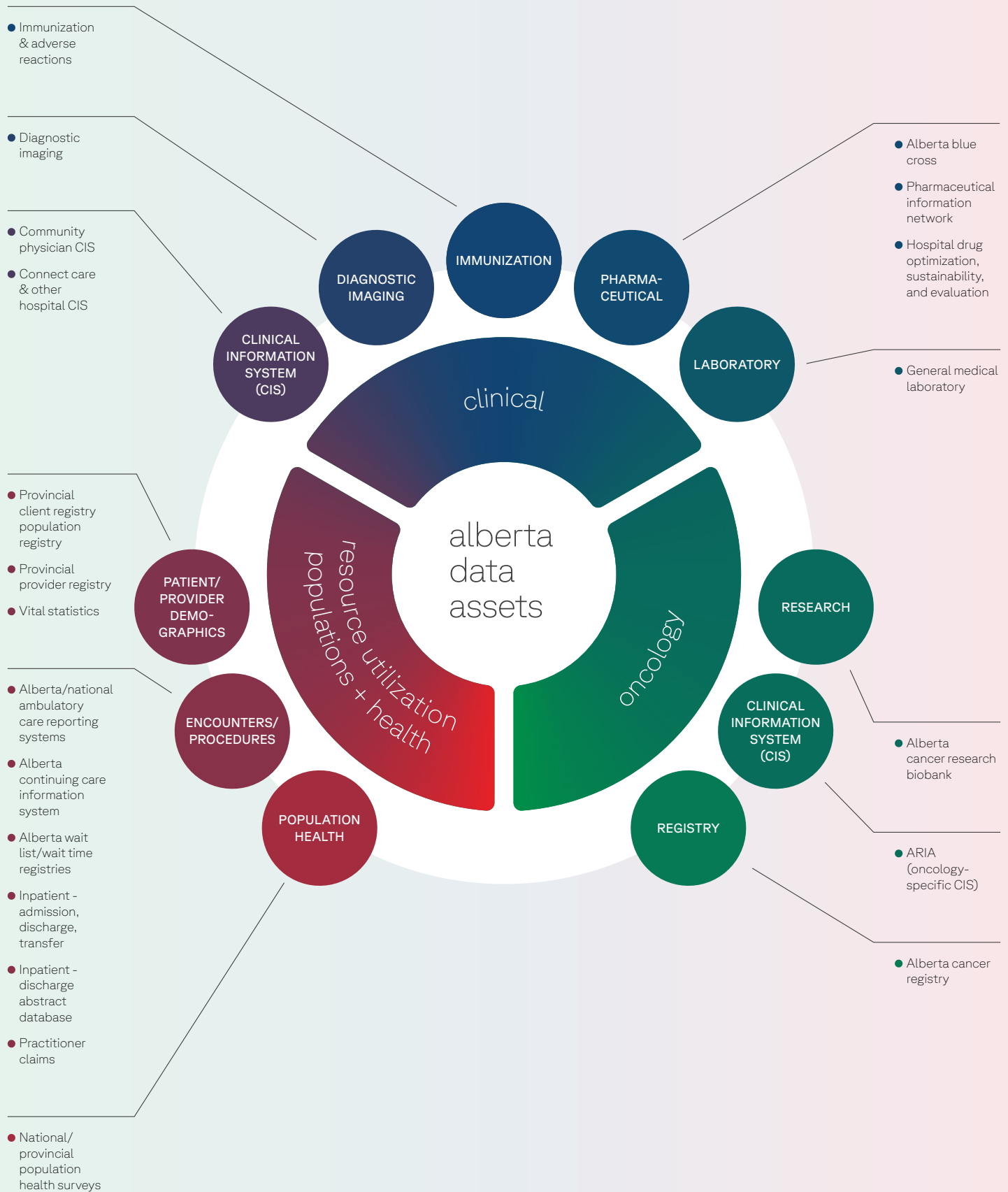
i.e. administrative and clinical data
specific to oncology

Updates

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 potential research projects that require unique data assets or outcomes, the Consortium will conduct a feasibility assessment to confirm data availability and accessibility.



data assets by name

- | | | | |
|----|--|----|---|
| 17 | <u>Admission, Discharge, Transfer (ADT)</u> | 14 | <u>Pharmaceutical Information Network (PIN)</u> |
| 13 | <u>Alberta Blue Cross Claims (ABC)</u> | 20 | <u>Population Health</u> |
| 17 | <u>Alberta Continuing Care Information System (ACCIS)</u> | 21 | <u>Population Registry</u> |
| 15 | <u>Alberta Perinatal Health Program (APHP)</u> | 20 | <u>Practitioner Claims (Fee-For-Service Claims, Supplemental Enhanced Service Event) (SESE)</u> |
| 15 | <u>Alberta Real Time Syndromic Surveillance Network (ARTSSN)</u> | 21 | <u>Provincial Client Registry (PCR)</u> |
| 18 | <u>Alberta Wait Times Reporting (AWTR)</u> | 22 | <u>Provincial Provider Registry (PPR)</u> |
| 18 | <u>Alberta Waitlist Registry</u> | 22 | <u>Provincial Registry</u> |
| 24 | <u>Canadian Community Health Survey (CCHS)</u> | 23 | <u>Vital Statistics</u> |
| 10 | <u>Canadian Primary Care Sentinel Surveillance Network – Alberta (CPCSSN AB)</u> | 23 | <u>Vital Statistics – Births</u> |
| 25 | <u>Canadian Tobacco, Alcohol, and Drugs Survey (CTADS)</u> | 24 | <u>Vital Statistics – Deaths</u> |
| 16 | <u>Communicable Disease Reporting System (CDRS)</u> | 26 | <u>ARIA (Oncology-Specific CIS)</u> |
| 10 | <u>Community-Based CISs (Electronic Medical Records) (EMR)</u> | 26 | <u>Alberta Cancer Registry (ACR)</u> |
| 11 | <u>Connect Care & Other Hospital CISs</u> | 27 | <u>Alberta Cancer Research BioBank (ACRB)</u> |
| 12 | <u>Consolidated Laboratory Data Repository (CLDR)</u> | | |
| 11 | <u>Diagnostic Imaging (DI)</u> | | |
| 14 | <u>Drug optimization, sustainability, and evaluation (DOSE)</u> | | |
| 12 | <u>Immunization and Adverse Reactions to Immunizations (Imm/ARI)</u> | | |
| 19 | <u>Inpatient - Discharge Abstract Database (DAD)</u> | | |
| 13 | <u>Medical Laboratory (General)</u> | | |
| 19 | <u>National Ambulatory Care Reporting System (NACRS)</u> | | |
| 25 | <u>National Health Population Survey</u> | | |
| 16 | <u>Perinatal</u> | | |

clinical data assets

Clinical Information System (CIS)

- 10 [Canadian Primary Care Sentinel Surveillance Network - Alberta \(CPCSSN AB\)](#)
- 10 [Community-Based CISs \(Electronic Medical Records\) \(EMR\)](#)
- 11 [Connect Care & Other Hospital CISs](#)

Diagnostic Imaging

- 11 [Diagnostic Imaging \(DI\)](#)

Immunization

- 12 [Immunization and Adverse Reactions to Immunizations \(Imm/ARI\)](#)

Laboratory

- 12 [Consolidated Laboratory Data Repository \(CLDR\)](#)
- 13 [Medical Laboratory \(General\)](#)

Pharmaceutical

- 13 [Alberta Blue Cross Claims \(ABC\)](#)
- 14 [Drug optimization, sustainability, and evaluation \(DOSE\)](#)
- 14 [Pharmaceutical Information Network \(PIN\)](#)

Other Clinical Databases

- 14 [Alberta Perinatal Health Program \(APHP\)](#)
- 15 [Alberta Real Time Syndromic Surveillance Network \(ARTSSN\)](#)
- 15 [Communicable Disease Reporting System \(CDRS\)](#)
- 16 [Perinatal](#)

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

populations & health resource utilization data assets

Encounters/Procedures

- 17 [Admission, Discharge, Transfer \(ADT\)](#)
- 17 [Alberta Continuing Care Information System \(ACCIS\)](#)
- 18 [Alberta Waitlist Registry](#)
- 18 [Alberta Wait Times Reporting \(AWTR\)](#)
- 19 [Inpatient - Discharge Abstract Database \(DAD\)](#)
- 19 [National Ambulatory Care Reporting System \(NACRS\)](#)
- 20 [Practitioner Claims \(Fee-For-Service Claims, Supplemental Enhanced Service Event\) \(SESE\)](#)

These assets contain data on populations (providers/patient demographics and population health) and encounter/procedure data.

Patient/Provider Demographics

- 20 [Population Health](#)
- 21 [Population Registry](#)
- 21 [Provincial Client Registry \(PCR\)](#)
- 22 [Provincial Provider Registry \(PPR\)](#)
- 22 [Provincial Registry](#)
- 23 [Vital Statistics](#)
- 23 [Vital Statistics – Births](#)
- 24 [Vital Statistics – Deaths](#)

Population Health

- 24 [Canadian Community Health Survey \(CCHS\)](#)
- 25 [Canadian Tobacco, Alcohol, and Drugs Survey \(CTADS\)](#)
- 25 [National Health Population Survey](#)

oncology data assets

Clinical Information System (CIS)

26 [ARIA \(Oncology-Specific CIS\)](#)

Registry

26 [Alberta Cancer Registry \(ACR\)](#)

Research

27 [Alberta Cancer Research BioBank \(ACRB\)](#)

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

>>> 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.

>>> 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.

researcher-initiated requests are currently handled on a case-by-case basis.

>>> 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	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.

>>> 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)

Category	Clinical
Focus area	Pharmaceutical
Start date	Apr 2008
End date	Present
Refreshes	Weekly
Custodian	Alberta Health/Alberta Health Services (AHS)

↳ 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 (HCDDPD) 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.

>>> Drug optimization, sustainability, and evaluation (DOSE)

Category	Clinical
Focus area	Pharmaceutical
Start date	Apr 2012
End date	Present
Refreshes	Monthly
Custodian	Alberta Health Services (AHS)

↳ Description

The DOSE data warehouse contains information from several systems across the province on patient specific prescription drugs dispensed from hospital pharmacies and automated dispensing cabinets. 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 and quantity dispensed. DOSE includes historical data from 2012 to current.

↳ Other Remarks

Cost information is not available, and the reason for the prescription is not captured. Information is on dispensed drugs (i.e. not prescriptions).

>>> 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.

>>> Alberta Real Time Syndromic Surveillance Network (ARTSSN)

Category	Clinical
Focus area	Other Clinical Databases
Custodian	Alberta Health/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.

>>> Perinatal

Category	Clinical
Focus area	Other Clinical Databases
Start date	2008
End date	Present
Refreshes	Not Required
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.

>>> 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
Refreshes	Daily
Custodian	Alberta Health/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

Category	Populations/Health Resource Utilization
Focus area	Encounters/Procedures
Start date	Oct 2003
Custodian	Alberta Health

↳ Description

The Alberta Waitlist Registry was publicly launched in October 2003 in response to the Premier's Advisory Council on Health report "A Framework for Reform", published in January 2002.

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)

Category	Populations/Health Resource Utilization
Focus area	Encounters/Procedures
Start date	Jul 2003
End date	Present
Refreshes	Monthly
Custodian	Alberta Health Services (AHS)

↳ 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.

>>> 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	Presentv
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 Services (AHS)

↳ 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.

>>> 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

Category	Populations/Health Resource Utilization
Focus area	Patient/Provider Demographics
Start date	Varies
End date	Present
Refreshes	Annually (fiscal year)
Custodian	Service Alberta/Alberta Health

↳ 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.

>>> Vital Statistics – Births

Category	Populations/Health Resource Utilization
Focus area	Patient/Provider Demographics
Start date	Jan 2005
End date	Present
Refreshes	Annually (fiscal year)
Custodian	Service Alberta/Alberta Health

↳ 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.

>>> 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.

>>> 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.

>>> 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 sociodemographic 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.



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