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Health data governance for research use in Alberta

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Abstract

Alberta has rich clinical and health services data held under the custodianship of Alberta Health and Alberta Health Services (AHS), which is not only used for clinical and administrative purposes but also disease surveillance and epidemiological research. Alberta is the largest province in Canada with a single payer centralised health system, AHS, and a consolidated data and analytics team supporting researchers across the province.

This paper describes Alberta's data custodians, data governance mechanisms, and streamlined processes followed for research data access. AHS has created a centralised data repository from multiple sources, including practitioner claims data, hospital discharge data, and medications dispensed, available for research use through the provincial Data and Research Services (DRS) team. The DRS team is integrated within AHS to support researchers across the province with their data extraction and linkage requests. Furthermore, streamlined processes have been established, including: 1) ethics approval from a research ethics board, 2) any necessary operational approvals from AHS, and 3) a tripartite legal agreement dictating terms and conditions for data use, disclosure, and retention. This allows researchers to gain timely access to data. To meet the evolving and ever-expanding big-data needs, the University of Calgary, in partnership with AHS, has built high-performance computing (HPC) infrastructure to facilitate storage and processing of large datasets. When releasing data to researchers, the analytics team ensures that Alberta's Health Information Act's guiding principles are followed. The principal investigator also ensures data retention and disposition are according to the plan specified in ethics and per the terms set out by funding agencies.

Even though there are disparities and variations in the data protection laws across the different provinces in Canada, the streamlined processes for research data access in Alberta are highly efficient.

Keywords

data governance; research data access; provincial and national legislatives

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Introduction

Under appropriate governance, health data generated from healthcare interactions are powerful sources of information for clinical, health services, and policy research [1]. Transparency about governance mechanisms and how personal health data are accessed and used for research are essential for public trust. Ensuring confidentiality, privacy, and secure handling of health data are fundamental principles that must be firmly built into the health data management processes of the data custodians and the data users. Secondary data sources like coded administrative data from hospital or clinic visits, laboratory test results, or pharmaceutical dispensing records, to name a few, include rich information. Healthcare consumers, clinicians, and researchers benefit when data about health and the use of health services are available for research within the parameters laid out by data governance policies and procedures [2].

In Alberta, Canada, residents, and researchers benefit from a single payer centralised health system managed primarily by Alberta Health Services (AHS) that includes a consolidated health Data and Analytics department [3]. This centralised health system enables the highest quality data governance with a streamlined data request and approval process. The volume and potential richness of Alberta's health data available to researchers are expanding with the rollout of a provincial comprehensive clinical information system, Connect Care (CC) based on an Epic platform [4, 5]. As such, throughout the data management lifecycle, mechanisms are established to ensure the safe handling of multiple sources of sensitive health information. This paper describes Alberta's data custodians, data governance mechanisms across the data lifecycle, available data resources, steps to be followed for data access, including direct access to clinical information systems for clinical studies, and the strengths and issues presented for researchers. The centralised data governance processes and sophisticated health data resources available in Alberta can inform other healthcare agencies striving to ensure high-quality data governance.

Population setting and stakeholder groups

Alberta has a population of 4.4 million and has a single-payer, free point-of-care health service funded by the Provincial Government Ministry of Health (i.e., Alberta Health (AH) [6]. As Canada's largest integrated health service, AH manages all acute care services. AHS employs ∼120k staff and physicians and provides, community care, emergency department, inpatient and some specialty outpatient services for residents of the province as well as tertiary care for residents of northern British Columbia, Saskatchewan, and the Northwest Territories.

Health data custodians in Alberta

In Alberta, there are two major custodians of health-related data. First, AH holds custodianship for an extensive list of administrative data, including the Population Registry capturing basic demographic information on residents in the province based on the Alberta Health Care Insurance Plan, Practitioner Claims to capture physician billing data, and Pharmaceutical Information Network (PIN) capturing the medications dispensed by community pharmacies [7]. Second, AHS holds custodianship for health services data, including emergency medical services (ambulance), emergency department, hospitalisation and discharge data, in-hospital diagnostic imaging, laboratory and electronic medical records [8]. Both organisations provide data access to researchers following standardised requirements and processes that comply with the Alberta Health Information Act (HIA) [8] and the Freedom of Information and Protection of Privacy Act (FOIP) [9]. The HIA stipulates rules and principles that govern and regulate Alberta's access, collection, use, disclosure, retention, and disposal of health information. In addition, HIA's guiding principles for data disclosure ensure the highest degree of anonymity by removing identifiers such as personal health number, date of birth, or complete postal code when releasing data, obtaining individual consent if collecting or using identifying data, and using the least amount of information to meet the research needs [8]. FOIP outlines rules governing access to public-sector data and the collection, use and disclosure of personal information [9].

As a custodian of health information, AHS has established several governance policies to protect the privacy and confidentiality of information. Some of these policies are listed in Table 1.

Historically data available for researchers to use contained only administrative data such as the Discharge Abstract Database and National Ambulatory Care Reporting System, including diagnosis codes, admission/discharge dates and dispositions. Over the last several years the data holdings have evolved to include clinical data, laboratory results, imaging, and other clinical indicators. In 2019, Alberta began to roll out an integrated provincial Clinical Information System EMR called CC, built by Epic Systems Corporation [10]. Before CC, Alberta had around 1,300 independent health information systems, which will now be replaced by CC when fully implemented by 2024 [11]. This implementation allows a central access point to patient information and best practices for healthcare providers [11]. When fully in place approximately 150,000 staff and physicians will use CC at 682 sites across Alberta. Several data sets commonly requested for research use are presented in Table 2.

Governance policies and standardarised processes

Both AH and AHS can disclose data to researchers and follow very similar governance policies and standardised processes to ensure the protection of research data throughout its life cycle. This manuscript describes the research data life cycle in four phases: 1) Plan and design, 2) Access or link data, 3) Release data, and 4) Data retention and disposition.

Phase 1: plan and design study

Research protocol and ethics

This phase involves developing a research protocol describing the study design and details about the data sources required,

Table 1: Alberta Health Services privacy policies

Records Management Policy	Outlines organization accountability for record management within Alberta Health Services (AHS)
Collection, Access, Use, and Disclosure of Information	Outlines collection requirements for collection, access, use, or disclosure, including health information, personal information, and business information under the umbrella of Alberta Health Services (AHS)
Information Security and Privacy Safeguards	Outlines safeguards and standards in Alberta Health Services (AHS) to protect the security, privacy, and confidentiality of information in the control and custody of Alberta Health Services (AHS)
Intellectual Property Policy	Outlines obligations and rights of Alberta Health Services (AHS) and intellectual property creators in the transfer, ownership, disclosure, commercialization, and revenue sharing of intellectual property
Official Records Destruction Procedure	Minimizes the risks associated with official record destruction, ensuring they are destroyed in a timely and safe manner
Privacy Impact Assessments Policy	Outlines the criteria, responsibilities, and process for conducting a Privacy Impact Assessment (PIA) within Alberta Health Services (AHS)
Privacy Protection and Information Access Policy	Outlines that only the personal and health information required for health care professionals to perform their responsibilities is collected, used, and shared within job duties
Non-Identifying Health Information Standard	Outlines organizational accountability for record management within Alberta Health Services (AHS)
Research Information Management	Supports Alberta Health Services (AHS) in the commitment to research with the goal of improving care, services, and systems in the health sector

and a plan regarding data collection, use and management. All research projects requiring access to health data must obtain approval from a regulatory research ethics board (REB) responsible for ensuring that the research is ethical and adheres to guidelines set out in the HIA of Alberta. Depending on the affiliation of the principal investigator (PI) and the type of health research, ethics application can be submitted to one of these REBs in Alberta: 1) Conjoint Health Research Ethics Board (CHREB) [12] which reviews all human participant health research, except cancer-related studies, conducted by PIs from the University of Calgary (UofC), 2) Health Research Ethics Board (HREB) [13] which reviews human participant health research applications, not cancer-related, where PIs are from University of Alberta (UofA), AHS, Covenant health, or the University of Lethbridge, and 3) Health Research Ethics Board of Alberta (HREBA) [14] which includes three committees; the Cancer Committee (HREBA-CC) which reviews cancer-related research studies conducted by PIs from UofA, UofC, AHS, covenant health or community, the Clinical Trials Committee (HREBA-CTC) for clinical trial studies conducted by physicians or other health professionals and the Community Health Committee (HREBA-CHC) for researchers without a UofC or UofA affiliation. The Alberta Research Information Services (ARISE) system [15] is used to submit research applications to HREB at the UofA, whereas, the Institutional Research Information Services Solution (IRISS) [16] is used for managing HREBA and CHREB research ethics applications at the UofC.

AHS review and approval

Upon approval of research by the REB, if the research ethics application specifies the requirement of AHS resources, including operational and/or requests for data from AHS, then the request gets automatically submitted to AHS for review and approval. This process is integrated into both the IRISS and ARISE systems. The Northern Alberta Clinical Trials and Research Centre (NACTRC) [17] in the Edmonton zone and AHS' Health Systems Access (HSA) team in all other zones [18] work with AHS staff, Alberta's academic institutions, affiliated research institutes and centres to facilitate the processing of research requests.

Research agreement

In the case of projects involving both research data and data for which AHS is the custodian, a contractual tripartite research agreement between the researcher, their affiliated organisation and AHS is established. The tripartite agreement dictates terms and conditions on all parties' data use, disclosure, and retention. The UofC and the UofA have legal review teams responsible for facilitating the execution of research contracts and agreements in collaboration with AHS. Depending on the type of health research, the tripartite agreement may not always be required and the type of tripartite research agreement varies depending on what the study entails. For example, a Clinical Trial Agreement (CTA) is required when clinical research is conducted on or for

Table 2: Commonly requested data sets for research use

Dataset	Description	Key variables
Discharge Abstract Database (DAD)	Hospitalizations for acute care patients in Alberta	• Mode of arrival • Length of stay • Critical care unit admission • Provider and patient service • Discharge disposition • Up to 25 diagnosis codes • Up to 20 intervention codes
Admission Discharge Transfer (ADT)	Patient location and transfers within a hospital	• Bed number • Room number • Unit number • Timestamps
National Ambulatory Care Reporting System (NACRS)	Emergency, same-day surgery, and day procedure encounters in Alberta	• Mode of arrival to emergency department • Triage level • Length of stay • Up to 10 diagnosis codes • Up to 10 intervention codes • Visit disposition
Emergency Department Information System (EDIS)	Emergency department visits that includes additional information to NACRS	• Presenting complaint • Patient location in emergency department • Visit timestamps
Pharmaceutical Information Network (PIN)	Prescription drugs dispensed from pharmacies within Alberta	• Drug identification number • Quantity dispensed • Days supply
Practitioner Claims	Health service claims submitted by providers for payment in Alberta under the Alberta Health Care Insurance Plan	• Provider speciality • Facility type • Up to 3 diagnosis codes
Laboratory	All general lab tests including clinical chemistry, hematology, toxicology, serology, urinalysis, and immunology in Alberta Health Services	• Lab type • Lab results
Provincial Registry	Identifies people with coverage under the Alberta Health Care Insurance Plan and can identify deaths within Alberta	• Date of death • Alberta Health Care Insurance Plan coverage for the fiscal year
Vital Statistics	Identifies dates for death for those in Alberta	• Date of death • Cause of death
Diagnostic Imaging	All diagnostic images that were performed in Alberta Health Services based facilities	• Encounter type • Time stamps • Exam priority • Modality • Body part • CPEL description

Continued

Table 2: Continued

Dataset	Description	Key variables
Alberta Continuing Care Information System (ACCIS)	Continuing care stay information including long-term care, home-living, and designated support living	• Admission and discharge date • Facility • Level of care • RAI assessments
Connect Care	The provincial electronic medical record	• Data availability on case-by-case basis

treatment of human subjects, [19]. A data disclosure can be done using either a tripartite agreement or, alternatively, with a Data Disclosure Agreement (DDA) depending on the parties and type of data involved. DDAs are managed only by Health Systems Access within AHS with the PI and AHS being the only two parties involved.

Phase 2: data access and extraction

AHS has several different data repositories and rules for access to data within each of them for research purposes is detailed within each repository's privacy impact assessment (PIA). These PIAs are reviewed by the Alberta's Office of the Information and Privacy Commissioner. Data custodians are required to submit a PIA for review by the OIPC (section 64 of the Health Information Act).

Upon approval for data access, the researcher can submit a request to the Alberta Strategy for Patient-Oriented Research SUPPORT Unit (AbSPORU) Data and Research Services (DRS) team for data extraction and analytical support as outlined in the research study protocol [20]. DRS is a team of masters and Ph.D.-trained senior data analysts based in Edmonton and Calgary, Alberta, and embedded within AHS Provincial Research Data Services.

AHS Data and Analytics maintains a centralised data repository on a secure server within AHS' firewall. The server houses patient-level administrative and clinical data from many different data sources, including hospitalisation and discharge data, diagnostic imaging, and laboratory services, amongst other data. The DRS team has access to the data repository and facilitates research studies by supporting data extraction and linkages, cohort derivations, and statistical analyses following AHS' policies and requirements stipulated in the Alberta HIA. Each analyst is responsible for completing AHS' mandatory Information Privacy & Security Awareness Training and signing a Confidentiality and User agreement before gaining access to AHS' systems and data. The DRS team supports researchers across Alberta with approximately 200 research requests facilitated annually.

Research use of data stored within AHS depends on permissions granted by the custodians of the data. Therefore, prior to proceeding with the fulfillment of the research request, the DRS team reviews the request. The team ensures there is proper consent in place or waiver of consent by the REB, that all data sources and time-period for data extraction are specified in the research ethics application, and all required agreements have been fully executed.

If a researcher requests data held under the custodianship of AH and stored in the AHS centralised data repository, such as the Practitioner Claims database, the DRS team must submit a request to AH to obtain approval for the research use of data. AHS and AH have an Information Sharing Agreement established, which stipulates that approval from AH is required for accessing and using data under the custodianship of AH for research purposes. The documentation needed for a request to AH includes:

- an ethics application and approval certificate,
- consent information,
- study proposal/protocol, and
- a list of data elements.

The DRS team also supports research studies requiring CC's EMR data. Like any other AHS system access, AHS network credentials and completion of specific training aligned with the user's role are required to access CC. The DRS analysts complete mandatory Epic proficiency training courses to understand the depth and structure of the CC system prior to accessing data. Currently, the DRS team is investing a considerable effort towards mapping data from previously used EMRs to CC, comprising more than 13,000 tables.

Clinical studies in connect care

CC also has research information management tools built into the system by the HSA team to support clinical studies. To gain direct access to CC, the clinical study REB application must state CC as a data source and indicate how the study plans to identify potential study participants using CC, specify the data that will be extracted, and the plan to protect extracted information. Only approved study members (i.e., those listed on the ethics application and legal agreement) are provided access to CC research management tools by HSA after completion of required training courses (eLearning courses and Research Staff Instruction Led Training) and passing of the Simulation End User Proficiency Assessment (SEUPA) with at least 80% score [21]. Observational studies requiring 'read only' access to CC to collect patient health data follow the same requirements of ethics approval, agreements with AHS and completion of specific training by research study staff before gaining access.

Research using multi-jurisdictional data in Canada

To facilitate data access to researchers interested in data from multiple jurisdictions, the Health Data Research Network Canada (HDRN) [22] was established, which is a network of organisations across Canada. HDRN's Data Access Support Hub (DASH) team follows a streamlined process that helps researchers throughout the data access process and provides support with navigating local requirements. HDRN's website provides detailed information on the intake and Data Access Request (DAR) for researchers. AbSPORU DRS [20] is the Alberta representative on DASH and collaborates with DASH and representatives from other provinces/territories to facilitate requests requiring Alberta health data.

Out-of-province researchers follow the same eligibility requirements for data access requests, including having a local Alberta PI and approval from an Alberta research ethics board. Generally, data must remain within Alberta except for aggregate results; however, in rare situations, it might be possible to release record-level data outside of the province, in which case a Data Transfer Agreement (DTA) between the researcher and AHS would be required.

Phase 3: data release

Upon completion of the research request by the DRS team, data gets released to the researcher. To securely transfer files, data is released using AHS' Secure File Transfer Protocol (SFTP)/ Globalscape Web Transfer Client. For releasing data to internal researchers, AHS' email services may be utilised to enable secure communications and file transfers. To ensure HIA's principle of sharing the least amount of information and maintaining individual identity is followed, the DRS team de-identifies data as appropriate, such as removing or encrypting patient identifiers such as personal health numbers and postal codes. However, some requests that require identifiable information may be permissible, such as, identifying a cohort of patients who meet a specific criterion to facilitate a researcher to conduct chart reviews.

Process, analyse and store data at the research institutions

Precision Health is a major strategic focus for the Cumming School of Medicine at the University of Calgary, and Faculty of Medicine and Dentistry (FOMD) and the College of Health Sciences at the University of Alberta. Accordingly, both institutions have built a secure High-Performance Computing (HPC) infrastructure to meet the growing demands of the research community. The HPC strategy was created in partnership between the University and AHS' health services. By establishing an agreement between the University of Calgary and AHS in conjunction with the development of the infrastructure, ensured that the AHS health system analysts were able to leverage the RCS asset while maintaining the governance including logging audit as required by the HIA.

At the UofC, the Secure Computing Platform, managed by the Research Computing Services (RCS), allows storage, sharing and processing of Level 2 (Internal) and Level 4 (Restricted) data in a secure environment [23]. In this platform, the Secure Computing Data Storage (SCDS) enables secure storage of data that can be accessed by approved users on a Restricted Managed Client Zone (Restricted Network) or through Data Analysis Tools virtual machines. SCDS does not support any devices that the University's IT department does not manage and cannot be used for storage or computing services through RCS. For data analysis, RCS offers the Advanced Research Computing cluster for processing Level 1(Public) and Level 2 data and the Medical Advanced Research Computing (MARC) cluster for processing Level 4 data [24].

To further expand the use of advanced computing platforms, an Information Management Agreement was established between the Governors of the UofC and AHS in 2020, enabling AHS' Analytics team to utilise the HPC. Per this agreement, the MARC cluster allows for storing and analysing AHS data, including EMR data. The UofC governs any AHS data on the cluster per the requirements of HIA, FOIP, and other applicable jurisdictional legislation and policies ensuring data confidentiality and protection against unauthorised access, use, disclosure, destruction, or alteration.

At the UofA, the Data and Analytics Research Core (DARC) provides high-performance computing (HPC) in a secure environment which helps researchers meet the privacy and security requirements for health data. At present, DARC includes multiple machines with over 3.8 TB RAM and 440 logical processors, including one GPU server with 8 x Tesla V100 GPUs and two new servers; Secure research data storage with over 20 TB available for local server storage. The DARC ensures secure data transfer with encryption and monitors all data going in and out of its environment. Its infrastructure includes multiple secure data centers, UPS battery backup and chilled water-cooling systems. It supports SAS Viya 3.5 which is an AI, analytic and data management platform as well as other software including R/Rstudio, STATA, Python and FACTS. The Lambda Labs GPU [23] component of DARC provides access to several machine learning platforms including TensorFlow, Keras, Caffe and CUDA.

Phase 4: data retention and disposition

Post completion of a research study, the PI is responsible for the retention and disposition of research records, including research data, according to the plan that the PI specified in the research ethics application [25]. Researchers must also follow the terms and conditions in the research agreement outlined by the data custodian when determining the time period for data retention or destruction. Generally, the ethics application requires researchers to specify a plan for any future data and destruction use. Some funding agencies may also have specific policies for preserving data for studies they fund. For instance, the Canadian Institute of Health Research requires data sets to be retained for a minimum of five years after the grant ends. Research institutions in Alberta provide resources to researchers about research data management. For example, the UofA has developed Research Records Stewardship Guidance Procedure which provides guidance on key considerations and requirements for research records retention [26].

To support Canadian research excellence by promoting data management and data stewardship practices, in 2021,

the federal Tri-Agency research funding organisations launched Research Data Management (RDM) policy and implemented it in stages. Per this policy, the postsecondary institutions and research hospitals administering Tri-Agency funds were required to create an institutional RDM strategy by March 1, 2023. As such, the UofA and the UofC have developed RDM strategies and aim to review their current policies, systems and processes and build onto them to create and maintain a robust RDM framework.

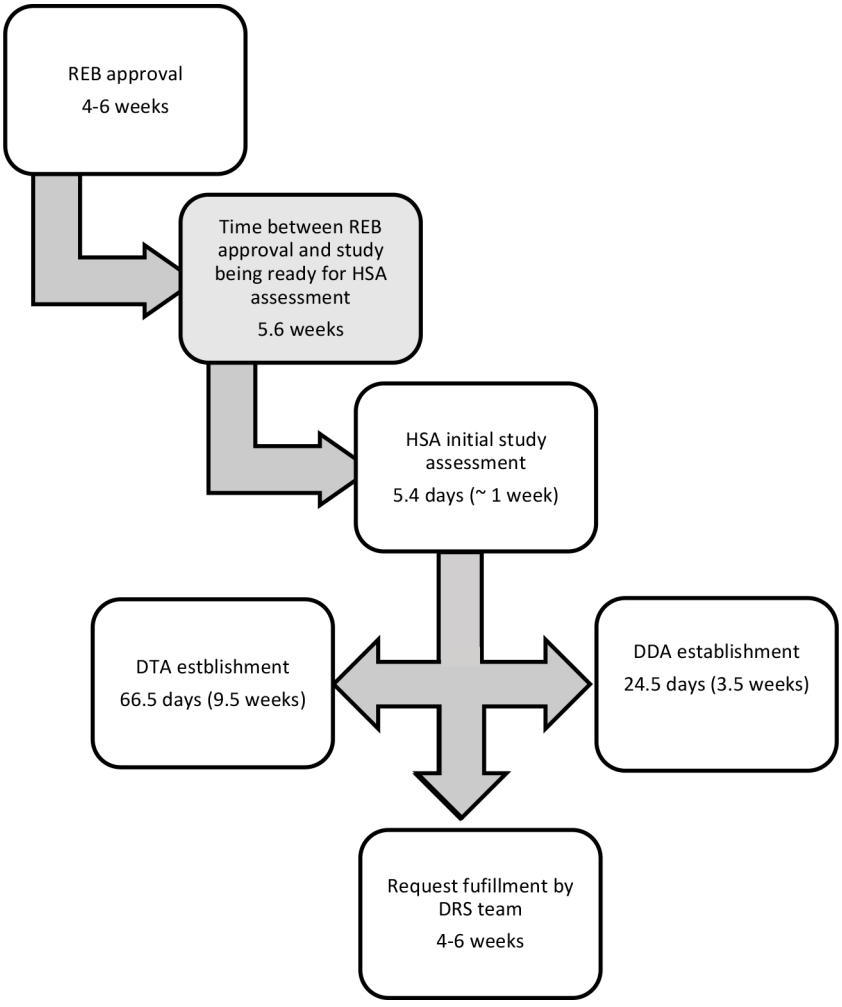
Average timelines for data access for research

Figure 1 provides average timelines for data access requests from researchers in Alberta. On average, an REB review takes approximately 4–6 weeks to approve a research study. This timeline is dependant on factors such as completion and clarity of the ethics application and response time by the researcher when clarifications are requested by an REB reviewer. The time between REB approval and study being ready for review by an HSA advisor averages at 5.6 weeks and is dependant on how long it takes a research team to supply the necessary information to HSA for study to be assessed. The initial study assessment by HSA and processing of a DDA takes, on average, 5.4 days and 24.5 days respectively. If a study requires operational approval, it takes 37 days which is running concurrently with the DDA processing. It is important to note that many studies that do not require operational approval which reduces the overall timeline for data access. Processing of a DTA, which is required when data is to be released to an out-of-province researcher, takes longer time, averaging at 66.5 days. There are scenarios that could potentially elongate data access timelines. For example, an HSA advisor determining that an amendment to the REB application or a change to an Informed Consent are required upon initial assessment of the study. The average timelines described here are inclusive of such scenarios and any periods that an HSA advisor may be awaiting a response from research team about any clarifications requested. Overall, this process upon REB approval can take an average of 11-15 weeks. Once the study receives AHS approval and research agreement (i.e. DDA) has been established, the DRS team within AHS processes the data requests and provides first output/report within 4–6 weeks of receiving the request.

Discussion

In this feature, we describe the health data available for research use in Alberta and the governance mechanisms, including standards and policies to access and use this health data. Alberta has rich clinical information that not only includes coded administrative data but also EMR data that can be used for clinical practice and secondary research.

Figure 1: Average timelines for data access requests in Alberta



AH and AHS support and promote research and clinical use of health data. Both organisations have established well-designed research policies and governance systems to protect the data held under their custodianship. One of the key strengths of conducting research using Alberta-based data is the consolidated single health authority, AHS, with centralised systems and teams following consistent, streamlined processes supporting researchers' access and process data in a timely manner. For instance, the AbSPORU DRS team is integrated within AHS and has analysts based in Edmonton and Calgary, two major cities in Alberta, with standardised processes for research intake and fulfillment of a request. The DRS team can support various data extraction and linkages and assist researchers across the province. For studies requiring multi-jurisdictional data, the national HDRN network helps researchers navigate local requirements for health data access, with the support of AbSPORU DRS, which helps facilitate requests requiring Alberta data. Furthermore, a partnership between academic institutions in Alberta and AHS has been established, allowing AHS' analytics team to use the high-performance computing infrastructure at the Universities for large data sets as well as research knowledge and education.

In Canada, data protection law is governed by a complex set of federal and provincial statutes with distinct personal health information protection laws and health-data governance mechanisms. At the national level, the Privacy Act of 1983 governs the regulation of personal information by the Government of Canada and the Personal Information Protection and Electronic Documents Act 2000 (PIPEDA) regulates commercial organisations, including health care providers funded through public health insurance systems that collect, use, or disclosure of personal information [27]. Some Canadian provinces, such as Quebec, British Columbia and Alberta, have provincial laws similar to PIPEDA. Therefore, PIPEDA may not apply to private sector activities in these provinces, except for data transfer across borders, provincial or national. In general, PIPEDA requires explicit consent to collect and disclose health data. However, a REB may grant a waiver for implied consent if specific criteria are met (e.g., TCPS, 5.5A, HIA), and exceptions may apply to data sharing while the Health Emergency Act is in place (e.g. pandemic). At the provincial level, the different provinces are regulated by different legislative acts. For example, Saskatchewan regulates under the Health Information Protection Act of 1999, Manitoba regulates under the Personal Health Information Act of 1997, and Ontario under Personal Health Information Protection Act of 2004. Sarabdeen et al. highlighted Canadian privacy law's 'fragmented and incomprehensive' nature. They emphasised the need for amendments to the existing law to align it with the European Union's General Data Protection Regulation (GDPR) to address data protection issues comprehensively [28]. Though the provincial laws in Canada may need amendments for interprovincial data sharing purposes and to align with one of the most comprehensive data protection laws (i.e., GDPR), the current processes in Alberta are well-streamlined and consistent and can be followed by both internal as well as external researchers.

There is still much to do to advance data linkage and sharing with the research community in Alberta. Provincial data has the potential to be linked with survey information on social determinants of health from sources such as the Canadian Community Health Survey and Canadian Health Measure Survey. It can also be enhanced by linking to other data sources such as education, social services, and non-AHS primary health care EMR data.

It is well-known that leveraging EMR data for research is promising, but a lack of data standards presents challenges for research usability. Alberta has the benefit of rolling out a standardised Clinical Information System across the province. To utilise this data in research training EMR analysts is key to fully understand the potential of the data. For example, this includes training analysts on new methodology (e.g., machine learning), how to reliably abstract data from unstructured data elements within EMR documentation and developing re-usable and automated queries. Data standards and processes need to be refined for utilising of EMR data by external researchers as it is challenging to release sensitive data for research purposes without removing all pertinent information.

Conclusion

In conclusion, the current research landscape is able to utilise Alberta's rich health data and promote using the data for 'better health' and 'better care' for patients. Data access and protection have been established for research use and with more use of the data, the richer and more useful the data will become.

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Statement of conflicts of interest

The authors declare there are no conflicts of interest.

Ethics statement

This study did not require ethical approval as the objective is to summarise the process that researchers need to follow to access data for research use.

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