**ACCESSING HEALTH DATA FOR RESEARCH IN ALBERTA**

**Identify Required Data Sources**
- Determine most suitable databases.
- Consult AbSPORU or CHI for available data at www.absporu.ca or chi@ucalgary.ca
- Identify data custodian (Alberta Health-AH), (Alberta Health Services-AHS) or others.
- Ensure permission for data elements is granted by data custodian.

**NOTE:** After obtaining ethics approval, AHS Health System Access (HSA) creates a file for project, and sends PI a Data Disclosure Agreement (DDA) form.

**Develop Research Proposal**
- Clearly state the rationale and objectives of the research and carefully detail the methodologic approach.
- For all required data sources, indicate if the data needs to be identifiable or can be de-identified.
- Specify how data will be safeguarded and participant privacy protected.
- See UofC resources on Ethics and Compliance and scroll to IT Guidance Documents.
- Consider drafting outpatient table shells.

**Obtain Research Ethics Approval**
- Ethics approval must be received before accessing health data for research.
- Ethics requires a detailed proposal proposal with analytic plan, budget, and plans for secure data storage.

**Data Disclosure Request**
A request to access health data should include:
- All required data sources include all databases and elements required, identifiable/de-identifiable.
- Where the data will be stored and analyzed securely (e.g. UofC versus AHS server).
- Any algorithms or definitions for capturing conditions that will be used.
- Data requests for research are made through AbSPORU via www.absporu.ca

**Data Disclosure and Release**
- Researcher must provide a ‘Schedule C’ — a list of variables requested from each source. Required by AHS and most data custodians.
- Upon data disclosure and release, arrangements are made with the custodian for data extraction and transfer.
- See UCalgary Research Computing Services for data storage and compute options.
- Begin analysis!

**NOTE:** Things that make for faster access to data:
- Provide AHS with ICD codes to identify the cohort to link and deidentify to study specifications.
- Request the least amount of data to address your research questions.
- Releasing data for sizable portions of the population may not be approved.
- Align all your data source dates to have a complete cohort.
- Data collected during the pandemic can be sensitive. Speak to an AbSPORU data analyst if you are requesting Covid or other potentially sensitive data (e.g. potentially identifying patients or providers).
- For extracting conditions, consider diagnosis codes, test or lab result formats, medication details (dose, frequency, start-stop dates).
- It is the researcher’s responsibility to ensure that their data request aligns with ethical standards, data privacy, and security requirements.
- The researcher must ensure that the custodian is willing and able to provide the requested data on the desired timeline before submission of a grant proposal, research contract or similar.
- It is not the custodian’s responsibility to make data available to the researcher. See “Health Research data access” for more information.