ACCESSING HEALTH DATA FOR RESEARCH IN ALBERTA

1. 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.

2. Identify Required Data Sources
   - Determine most suitable databases.
   - Consult AbSPORU or CHI for available data at www.absporu.ca or chi@ucalgary.ca available data and feasibility of data access.

3. Obtain Research Ethics Approval
   - Ethics approval, data disclosure agreement, and AHS Administrative Approval are required before accessing health data for research.
   - Ethics requires a detailed proposal with analytic plan, budget, and plans for secure data storage.

4. 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

5. Data Disclosure and Release
   - Researchers should collaborate with AHS analysts to provide a list of data elements required for the study.
   - Upon data disclosure and release, arrangements are made with the custodian for data extraction.
   - 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; other communicable disease data).
- 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.

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