UNIVERSITY OF CALGARY
CUMMING SCHOOL OF MEDICINE
Centre for Health Informatics

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

START

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

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

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.

NOTE: Consult CHI for support with:

- Proposal development
- Data storage options
- Analysis plans
- Data sources can affect timelines. Obtain a letter of support from the data custodian for less common or sensitive datasets.

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!

FINISH

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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