

Data Disclosure using the Five Safes Framework

Best Practices for Researchers

Alberta Health Services (AHS) is a custodian of health information as defined by the [Health Information Act](#) (HIA). In accordance with the HIA, AHS can disclose information to facilitate research under certain conditions. The purpose of this document is to provide researchers with guidance on the best practices for requesting and accessing data, ensuring compliance with the HIA and AHS standards. Following these guidelines will expedite the review process and streamline the release of data.

Prior to disclosing information to support research, all data requests are evaluated using the [Five Safes model](#), an internationally recognized framework designed to ensure safe and secure disclosure of data. Developed by the UK's Office of National Statistics, this model is widely used by various organizations across the world and Canada including the Government of British Columbia, Population Data BC, Statistics Canada, and the New Brunswick Institute for Research. Data requests are evaluated against five dimensions: safe projects, safe data, safe people, safe setting, and safe output. Researchers must adhere to all five dimensions, demonstrating their commitment to ethical standards and responsible data usage.

When submitting a data request, please keep the following considerations in mind:

- **Evaluation Factors:** Several factors impact the evaluation of a request, including the presence/absence of patient consent, the identifiability of the data, data sharing plans, intent to create a registry, involvement of artificial intelligence, and intent to commercialize. Such factors may increase the complexity of your request and may require a more detailed review.
- **Collaboration Benefits:** Consulting and collaborating with internal AHS teams can greatly enhance your research. AHS, through its various specialized data sciences teams, has extensive experience in collaborating with researchers to provide data and, in some cases, analytics services for a wide range of research projects.
- **Custodian Requirements:** Obtaining ethics approval does not guarantee access to data. As a custodian of health information, AHS is committed to complying with the principles of the HIA and may impose additional conditions in addition to those listed by the Research Ethics Board.
- **Personal Identifiers:** Personal identifiers, such as Personal Health Number and date of birth, are only released when essential to the research project and requests for this information will undergo a more detailed review. Note that personal identifiers are not released for the purpose of linking to other AHS datasets; such linkages are performed internally by AHS analytics teams.
- **AHS Setting:** Agreeing to maintaining data and/or models within AHS servers can help expedite the review process.

To expedite the processing of your data request and enable a prompt review, please consider the following guidelines:

Safe Projects

- Include a completed [application form](#), research proposal, and evidence of ethics approval from an Alberta Research Ethics Board.
- Ensure consistency across all submitted documents including the application form, research proposal and the ethics application.
- Ensure your research objectives are well-defined and specific. Avoid broad or vague questions; instead focus on a specific aspect of your research topic.
- Narrow your cohort to a specific and well-justified subset of the population that is relevant to the research objectives. Specify the timeframe and any other relevant parameters.
- Include a detailed analytical plan outlining the methods and techniques you will use for data analysis as appropriate for your stated objectives.
- Provide shell tables or similar structured formats to outline the expected output.
- Your research proposal and analytic plan needs to provide justification for the data elements you have requested.
- Demonstrate the relevance to the provision of healthcare.
- If applicable, state any plans for commercialization.
- Specify if you are collaborating with an industry partner or a pharmaceutical company.
- Identify the entity providing the funding for the project.
- If applicable, ensure that patients have provided consent for the intended use and collection of data, since this will impact the type of data that may be disclosed and shared externally.

Safe Data

- Only request variables that are essential to your current research questions.
- Identifiers, as defined by the [AHS non-identifying health information standard](#), should only be requested if they are essential to your research project. Examples include personal health number (PHN), hospital chart number, name, address, postal code, date of birth, and date of death. Ensure that you provide a thorough justification detailing why each identifier is essential and how it will be used in your research. Personal identifiers will not be released for the purpose of linking with other AHS datasets; such linkages must be performed internally by AHS teams.
- For projects involving chart reviews, limit the number of patients' PHN's requested to an amount that addresses your research questions and can be feasibly conducted within the resourcing and timeframe of your project.

- Given the implementation of Connect Care, some chart review projects can be done more efficiently and safely using data extracts. You should consider using data extracts for such projects.
- The requested data should be used solely for the proposed project.

Safe People

- Demonstrate that you and your team have the knowledge, skills and experience to analyze, use and interpret data responsibly.
- Engage with AHS data and analytics teams ([Data & Analytics](#)) [Cancer Surveillance & Reporting](#)) to address any questions you may have about the data / analyses.

Safe Settings

- Clearly identify how and where data will be securely stored, used, and analyzed.
- Maintain data on AHS servers whenever possible.
- Never share data with third parties unless appropriate data transfer agreements clearly specifying the arrangement, are in place with AHS.

Safe Output

- Provide an outline of the expected output (e.g., shell tables).
- Ensure that all results produced are only released in aggregate form.
- Ensure that outputs do not inadvertently reveal sensitive information.
- Specify any plans for data sharing and/or registry creation and ensure appropriate agreements with AHS are in place prior to initiating this type of work.

Note: Projects leveraging artificial intelligence/machine learning methods are subject to further detailed review to ensure compliance with privacy, ethical, and regulatory considerations.

Overview of the Data Access Process

1. The process is initiated when a data request is submitted (application forms can be found [here](#)).
2. An initial assessment is conducted to verify the completeness of the data request and ensure consistency across all submitted documents. The initial assessment also involves determining the type of review that is required.
3. Regular data requests undergo a standard review, while more complex or sensitive requests require a comprehensive review. The review stage may involve representatives from various AHS departments including Data & Analytics, Cancer Advanced Analytics, Health System Access, AHS Privacy, AHS Legal, and other relevant departments. Alberta Health may also be consulted in cases involving data under their governance.
4. A request can be approved, rejected, or sent back for amendments.
5. Administrative approval and the execution of an agreement are required prior to the release of data.

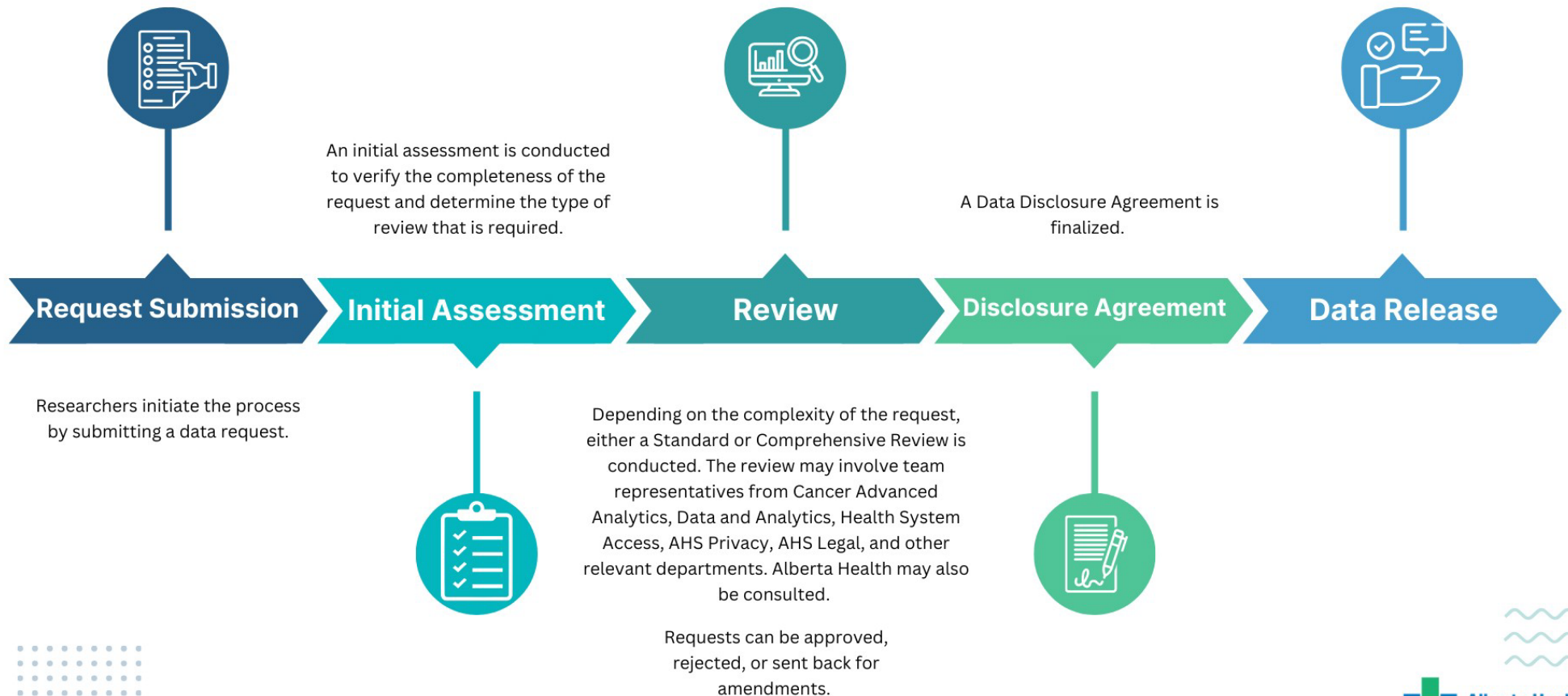
Note: The timelines for processing data access requests can vary widely depending on several factors, including, but not limited to the:

- complexity of the request
- completeness of the application
- consistency across the submitted documents
- response time of the researchers when asked for additional information
- number of analytic teams involved
- capacity of the analytic teams involved

While straightforward requests may be processed in as little as a few weeks, more complex requests can take several months to complete.

Please refer to the visual on the next page for an overview of the access process.

Data Access Process



Request Submissions:

- Data and Analytics (DnA): [Service Application - AbSPORU](#)
- Cancer Surveillance and Reporting (S&R): [S&R Data Request Form \(albertahealthservices.ca\)](#)

Contact Information

For questions or further assistance, please contact:

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