Saskatchewan Cancer Agency
Frequently Asked Questions about Data Requests

The Saskatchewan Cancer Agency supports quality research, data use and collection towards improving cancer control. Having a clear and transparent process for data requests will allow for timely and appropriate access. The information below addresses some of the frequently asked questions around data requests that the Saskatchewan Cancer Agency receives.

Who can request data or information?

Researchers, academics, health professionals and other persons may request data or information.

What is the difference between information and data?

The term 'data' generally refers to unprocessed information, while the term 'information' refers to data that have been processed in such a way as to be meaningful to the person who receives it. For the purpose of this document 'data' and 'information' are used interchangeably and should be taken to mean both data and information.

What types of data requests are accepted?

The type of data requests accepted are administration, clinical study, research, and quality assurance (QA)/quality improvement (QI).

What is the difference between research and quality assurance/quality improvement?

Research and quality assurance/improvement have much in common. However, research is defined as an investigation conducted through a disciplined inquiry or systematic investigation for the purposes of contributing to or developing generalizable knowledge. In most cases, these findings are published.

Quality Assurance (QA) measures compliance against certain necessary standards. QA is required for the quality improvement (QI) processes. QI is a continuous improvement process. It is a proactive approach to improve processes and systems.

What types of data are available?

Aggregate data	Summed and/or categorized data that are analyzed and placed in a format that precludes further analysis (for example, in tables or graphs) to prevent the chance of revealing an individual's identity (ensures that individual records cannot be reconstructed). Aggregated data do not include personal health information (PHI).

Anonymized data	Information or materials have been "irrevocably stripped of direct or indirect identifiers, a code is not kept to allow future re-linkage, and risk of re-identification of individuals from remaining identifiers is low or very low". For research involving secondary analysis of anonymized data, where there is a possibility of data linkage and/or threat to the confidentiality and anonymity of said data, ethics review and Saskatchewan Cancer Agency approval are required.
De-identifiable data	Data that include elements that may constitute identifying information because there are reasonably foreseeable circumstances in which the data could be utilized, alone or with other information, to identify an individual (e.g., if linked with publicly available data). Thus, de-identified record-level data may contain PHI.
Identifiable data	Data that include elements that directly identifies an individual. By definition, identifiable record-level data contains PHI. For example, record level data containing PHI.
Published data	Data that are made available to the public. Published data should not include PHI.

What databases are available at the Saskatchewan Cancer Agency?

The Saskatchewan Cancer Agency databases are the cancer registry, the cancer screening databases, the clinical management system, the hematology database and the pharmacy database.

What type of data are available in the databases?

Data Set	**Description**
Cancer Registry	Captures population-based cancer-related data on every cancer case diagnosed for Saskatchewan residents.
Cancer Screening Databases	Contains information on all Saskatchewan residents qualifying for breast, cervical and colorectal screening.
Clinical Management System	Electronic medical record of people diagnosed with cancer including treatment.
Hematology Database	Contains information on people with a hematologic cancer diagnosis.
Pharmacy Database	Contains information on all cancer patients receiving prescriptions for oncology drugs.

How do I request access to Saskatchewan Cancer Agency data?

Individuals who want access to Saskatchewan Cancer Agency data are required to complete a data request form and send it to datarequest@saskcancer.ca. A data expert will review the submitted form and provide it to the Saskatchewan Cancer Agency's Data Access Committee (DAC) for review and approval. The requestor will be notified in writing once the DAC has made a decision on the request.

Who is a data expert?

A data expert is a Saskatchewan Cancer Agency employee who has extensive knowledge of the type of data available through a specific database.

What is the Data Access Committee (DAC)?

The DAC is a committee of Saskatchewan Cancer Agency staff authorized to review and approve access to and use of data.

What is the purpose of DAC?

The purpose of the DAC is to ensure that data are released in a responsible and accountable manner that supports efficient, effective and appropriate use.

What is the process for a data request to be accepted or denied?

The DAC will review the data request form submitted using a ranking tool that looks at feasibility, importance of research, funding availability, scientific merit and validity.

What does an approved data request mean?

An approval means the DAC has agreed to proceed with the data request. A letter will be sent indicating the project has been approved and a data expert will contact the requestor.

What does a declined data request mean?

A declined data requests means the DAC did not approve the requestor's data request. A letter will be sent explaining the reasons the request was not approved.

Is there an appeal process?

Yes, there is an appeal process. The data requestor has 30 calendar days from the date of the denial letter to submit a request for reconsideration form. The request for reconsideration needs to provide additional information and address the reasons why the original request was denied.

What do I do if I want to amend my original data request?

To amend an original data request, the requestor needs to provide additional information and resubmit the original data request form with the additional information.

Is ethics approval required for all data requests?

No, ethics approval is not required for all data requests. Ethics approval is only required for a research project.

Does cost recovery apply to all data requests?

There is a guideline document on cost recovery for data requests. Cost recovery is dependent on the nature of the data request.

How do I estimate the cost of my data requests for the purposes of a grant submission?

The data expert will work with the requestor for a cost estimate, once the data request form has been submitted.

How long will it take to process my application?

The Data Access Committee meets monthly and our goal is to review your application within **three months**.

What is the timeline to receive the data/information once approved?

The goal is to provide the data in the shortest timeframe possible. There are a number of factors which will influence the timeline. For example:

- if a similar request is on file and only minor modifications are needed to generate the information requested, the timeframe will be shorter;
- if the request requires the review of multiple data sets it will take longer to complete.

How does the Saskatchewan Cancer Agency protect the information in the databases?

The Saskatchewan Cancer Agency is bound by *The Cancer Agency Act* and *The Health Information Protection Act* which outline its responsibility to protect personal health information. Under this legislation, the Saskatchewan Cancer Agency must only release the minimum amount and the least identifiable information required to meet the intended purpose and use identified on the data request form.

Why can you not provide data with full postal codes?

When combined with other information, a postal code can identify individuals. To ensure the privacy of patients, the Saskatchewan Cancer Agency's standard practice is to provide only the first three characters of the postal code.

If the requestor requires the full postal code, the proposal should clearly state why full postal code information is required. The Saskatchewan Cancer Agency is the trustee of our own data, so we have the final authority over the release of any data even if there is Research Ethics Board (REB) approval for a project.

What is the standard for releasing or reporting information on small sample sizes?

Small sample sizes should not contain any level of detail that might identify individuals. Any identifying characteristics that can be used to single out individuals will be removed prior to the release of information, regardless of the count size. This can include items such as race, residence, place of care, health-related risks and other identifying factors.

Counts less than five (5) containing information about behaviors, conditions or treatments that may be considered socially stigmatizing shall not be used in reports. This includes information on sexually transmitted diseases, substance abuse, mental health and information related to sexuality and reproductive health.

Counts less than five (5) that do not include sensitive information can be released at the discretion of the Saskatchewan Cancer Agency provided they do not contain any characteristics that can identify individuals.

All count-only reports need to be accompanied with a disclaimer about the expected use of the information and are subject to privacy rules under *The Health Information Protection Act*.

How long may I retain the data?

Data disclosed by the Saskatchewan Cancer Agency can only be retained for the period outlined in the data access agreement for the project. Requestors must return or destroy all data provided by the Saskatchewan Cancer Agency within the timeframe indicated in the data access agreement.

Whom do I contact for further information?

For more information, you can contact our coordinator at datarequest@saskcancer.ca.