FOR ADMINISTRATIVE USE ONLY

Request number: Version:

Date received: Date DAC Approved:

Application to Access Data and/or Conduct Research at the Saskatchewan Cancer Agency

INSTRUCTIONS:

- This form is to be completed when requesting data, held by or entrusted to the Saskatchewan Cancer Agency, that will be used for secondary purposes such as research, case studies and QA/QI projects with the intent to publish, present, or release the data or the QA/QI project may impact multiple data systems. This includes identifiable, aggregate, de-identified or anonymized data. See definitions on page 7.
- Filling out the form in Adobe: Using the tab or arrow keys the cursor will advance to the next input field. Checkboxes may be checked by clicking with a mouse. Once completed, sign below and email the form and any supporting documentation to datarequest@saskcancer.ca
- If you have any questions or require further information regarding data content, please contact us at datarequest@saskcancer.ca

NOTE:

- This application **must** be completed in full by the Principal Investigator
- It may take up to 3 months to process your application so please submit early and ensure completeness to prevent any delay in processing your application.
- The Saskatchewan Cancer Agency is a trustee of our own data and are a separate organization from the Saskatchewan Health Authority

1. IDENTIFICATION

1.1. Project Title: Title of Project

1.2. Principal Investigator

Name: First Name Last Name

Role/Title: Enter the role/title at current organization

Name of Organization: Enter the name of the organization under which the Principal Investigator is requesting the data

Mailing Address: Address, City, Province, Postal Code

Email:

Phone:

1.3. Primary Contact Person for Correspondence (if different than section 1.2)

Name: First Name Last Name

Role/Title: Enter the role/title at current organization

Name of Organization: Enter the name of the organization under which the Principal Investigator is requesting the data

Mailing Address: Address, City, Province, Postal Code

Email:

Phone:

1.4. Project Personnel (including graduates/post graduates/residents)

- Please list all persons involved who will need access to Agency data (e.g. principal investigator, co-investigators, students, etc.)
- For each individual identified, select what type of data they require access to (this selection will be the data they are initially looking at).
- List **all** individuals who will be accessing Agency data, whether they plan to come into an Agency location to do the research or have the data de-identified and distributed to them.

Name		What type of data do you require access to? ☐ Aggregate ☐ Anonymized ☐ De-Identifiable ☐ Identifiable Record Level ☐ Self-Review Chart Access ☐ Patient contact (e.g. survey/brochure)
Project Position/Role:		
Email:		
Phone:		
Notes:		

Name		What type of data do you require access to? ☐ Aggregate ☐ Anonymized ☐ De-Identifiable ☐ Identifiable Record Level ☐ Self-Review Chart Access ☐ Patient contact (e.g. survey/brochure)
Project Position/Role:		
Email:		
Phone:		
Notes:		

Name		What type of data do you require access to? ☐ Aggregate ☐ Anonymized ☐ De-Identifiable ☐ Identifiable Record Level ☐ Self-Review Chart Access ☐ Patient contact (e.g. survey/brochure)
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Name		What type of data do you require access to? ☐ Aggregate ☐ Anonymized ☐ De-Identifiable ☐ Identifiable Record Level ☐ Self-Review Chart Access ☐ Patient contact (e.g. survey/brochure)
Project Position/Role:		
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Name		What type of data do you require access to? ☐ Aggregate ☐ Anonymized ☐ De-Identifiable ☐ Identifiable Record Level ☐ Self-Review Chart Access ☐ Patient contact (e.g. survey/brochure)
Project Position/Role:		
Email:		
Phone:		
Notes:		

1.5. Proposed Project Period:

From: Date you intend to begin your project

To: Date project ends (e.g., analysis complete and publication drafted)

1.6. Specify any time considerations the Agency should be aware of (e.g. short enrolment period):

Provide a brief explanation

1.7. Has this project applied for/received ethical approval from a Saskatchewan Ministry of Health approved Research Ethics Board (REB)?

☐ Yes If yes, specify where:
☐ No If no, specify why:

1.8. Is this project funded in any way?

☐ Yes ☐ No

If yes, state source: Specify where the funding will be coming from

Dollar amount: Specify the amount you are applying for an/or received

Is the project completion contingent on funding?

☐ Yes ☐ No ☐ N/A

1.9. Publication Information

Results to be published, presented, or released, etc.?

☐ Yes ☐ No

If yes, please list where: If known at this time, please identify where you plan to publish your results. Note: all publications must be reviewed by members of the Data Access Committee and Public Affairs

2. SPACE REQUIRED

If someone from the project requires physical space to work within an Agency facility, complete the information below.

2.1. Additional space required?

☐ Yes ☐ No

2.2. Facilities space location

☐ Regina ☐ Saskatoon

2.3. Internal requestors – if you are bringing an external student/person in, will they use the following?

☐ Own office/department ☐ Require additional space

2.4. List the name(s) of those that will require additional space below: ONLY complete this section if you checked yes in section 2.1

Name	
Timeframe:	From: To:
Equipment Required:	

Name	
Timeframe:	From: To:
Equipment Required:	

Name	
Timeframe:	From: To:
Equipment Required:	

Name	
Timeframe:	From: To:
Equipment Required:	

3. OVERVIEW OF RESEARCH PROJECT

3.1. Research Purpose/Hypothesis and Clinical Relevance.

Briefly describe the purpose/hypothesis of the project, stating the question to be examined and the clinical relevance of the findings.

4. DATA REQUIREMENTS

4.1. Intent of Request

- ☐ Research Study
- ☐ Case Study (1-2 cases)
  - If checked, do you have patient consent? ☐ Yes ☐ No
- ☐ Quality Assurance/Improvement
  - For the purposes of planning, delivering, evaluation, or monitoring a program of the Agency?

Note: If no to all options above, please contact the Agency Privacy officer at privacy@saskcancer.ca to determine the legislative authority to disclose Agency data under applicable provincial legislation.

- ☐ Other:

4.2. Study Type

- ☐ Prospective
- ☐ Retrospective

4.3. What level of data do you require access to?

(Check off the most identifiable level of data you will be accessing)

- ☐ Aggregate Data (statistics only)
- ☐ Anonymized Data
- ☐ De-identifiable (case list without identifiers)
- ☐ Identifiable Record-Level Data
- ☐ Direct Patient Contact

4.4. Indicate from which sources personal and health information data will be collected (check all that apply):

- ☐ eHealth Saskatchewan Must have operational approval to use the eHR viewer for research purposes
- ☐ Health Quality Council
- ☐ Physician or other private health care professional office records
- ☐ Saskatchewan Health Authority – specify Region, Site & Dept.
- ☐ Saskatchewan Ministry of Health
- ☐ Saskatchewan Cancer Agency
- ☐ Other (please specify):

Note: The organization, custodian or trustee of the data must be aware of this access and use and, in some cases, must provide operational approval for the access/use.

4.5. What is the estimated sample size (records/cases/charts) required for your project?

Enter how many participants you plan to do your research on

4.6. Data Access Needs

In order to receive Agency data, please read through the options listed below and check off all that apply.

☐ **Option 1.** If you do not need access to our patient records and only require a generated list of data, an electronic transmittal file will be provided to you through a password electronic protected email.

File Format

- ☐ CSV (comma separated values)
- ☐ MS Excel Format

☐ **Option 2.** If the PI, students, and/or any other co-investigators plan to manually abstract the data themselves, a secure account and folder will be provided on the Agency network to save the data and any working files. Remote access may be possible from any location that has internet access upon Agency approval.

In what format is the data you intend to access?

- ☐ Paper medical charts
- ☐ Electronic medical charts If known, which Agency software platform do you intend to use?
- ☐ Unknown

☐ **Option 3.** If neither of the options above apply to you, select option 3 and provide an explanation.

If neither of the options above apply to you, select option 3 and provide an explanation

5. PATIENT CONTACT

For more information on Agency recruitment methods, please refer to the Surveys and Posters document located on the Agency website at www.saskcancer.ca/datarequests

5.1. Will the patient be contacted? (If no, skip to section 6)

☐ Yes ☐ No

If yes, check all which apply

- ☐ Survey
- ☐ Brochure
- ☐ Posters
- ☐ Other, please specify:

6. DATA ELEMENTS

Please list all data elements required, this **must** be completed.

6.1. List all required data elements in the table below or attach a list with your submission. (e.g. demographics, diagnostics, treatment, screening, etc.)

DATA ELEMENT(s)			

Please note: The 'day' component of certain date fields **will not** be provided and only the first three digits of the postal code **will** be released. For more information please refer to the Frequently Asked Questions document located on our website at www.saskcancer.ca/datarequests

6.2. If you did not list the data elements in the chart above, confirm you have attached the list.

☐ Yes ☐ No

7. SIGNATURES

7.1. Saskatchewan Cancer Agency EMPLOYEE USE ONLY

The Principal Investigator assumes responsibility for ensuring the following individual has approved their request prior to submission.

Approving Director/VP Printed Name (Do not need signature)

First Name Last Name

7.2. Declaration by Principal Investigator

- I confirm that the information provided in this application is complete and correct.
- If personal health information is requested, I assure that it is the minimum necessary to meet the research objective and will not be reused or disclosed to any parties other than those described in this form, except as required by law.
- I will report to the Data Access Committee (DAC) any significant changes to the project, including the proposed method, consent process or recruitment procedures, and data elements for review and approval by the DAC by revising the 'Application to Access Data and/or Conduct Research at the Saskatchewan Cancer Agency'.

PRINCIPAL INVESTIGATOR

Printed Name: Date:

Signature: _____

8. ATTACHMENTS

Provide a full and accurate listing of all documents submitted with this application.

Document	Included?	Comments
REB Application	☐ Yes ☐ N/A	
Certificate of Approval or Exemption from REB	☐ Yes ☐ N/A	
Protocol/Proposal	☐ Yes ☐ N/A	
Grant Application (if applicable)	☐ Yes ☐ N/A	
Other documents	☐ Yes ☐ N/A	

DEFINITIONS:

1. **Aggregate Data:** Summed and/or categorized data that is 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 (individual records cannot be reconstructed). Aggregate data does not include PHI.
2. **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 data 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 Agency approval is required.
3. **Data:** Raw variables or fields that are sourced from any Agency holdings.
4. **De-identified Record-Level Data:** Data that includes elements that may constitute identifying information because there may be 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.
5. **Identifiable Record-Level Data:** Data that includes elements that directly identifies an individual. By definition, identifiable record-level data contains PHI.
6. **Information:** Data that has been processed, organized, structured or presented in a given context after analysis so as to make it useful.
7. **Personal Health Information (PHI):** As defined in section 2(m) of HIPA3.1 and referenced in policy IMS 00013.2.
8. **Primary use:** The primary purpose of data collected by the Agency is to support the diagnosis, treatment and care of an individual.
9. **Published Data**: Data that is made available to the public through presentations, publications, and releases. Published data does not include PHI.
10. **Quality Assurance (QA):** Quality assurance (QA) measures compliance against certain necessary standards. Quality improvement is a continuous improvement process. QA is required and normally focuses on individuals.
11. **Quality Improvement (QI):** Quality improvement is a continuous improvement process. QI is a proactive approach to improve processes and systems.
12. **Secondary use:** Refers to the disclosure of data for a purpose other than that for which it was originally collected. In secondary use, patient or client data that has already been collected would typically be used in aggregate.