

Saskatchewan Cancer Agency Overview of Process to Complete your Data Access Project

Every data request that receives approval must follow the steps outlined below throughout their project. The data expert assigned to your request or our coordinator will be there to assist you throughout the process. If you need further information, please discuss this with the data expert assigned to you or connect with our coordinator through e-mail at datarequest@saskcancer.ca.

1. Research Agreement

Each approved project will require an agreement with the Saskatchewan Cancer Agency. Your data expert and our agreements specialist will work with you to define your project and gather any further information needed to complete the research agreement. This will include a complete data list and your ethics approval/exemption letter if not already provided. If you are not an employee or a physician under contract to the Agency, the agreement will also include a confidentiality agreement.

Once the agreement is signed you will be accountable for the contents of the agreement. Therefore if you have questions, please contact our legal counsel for further clarification before you sign the document. Your project cannot proceed and you will not be provided/allowed access to data/information until this agreement is fully executed. Once the agreement is signed, if you wish to change anything within your project, the agreements specialist and data expert will need to work with you to do an amendment of the agreement. If the change is substantial, your project may need go back to the Data Access Committee (DAC) for further consideration and another decision regarding approval.

2. Payment (if Applicable)

If you are paying the Saskatchewan Cancer Agency for the work on your project (i.e. you have grant funds or some other funding source), our coordinator will provide you with an invoice (as outlined in your research agreement) and once paid we can proceed. If you are asking to access patient information yourself or through a student/affiliate, you are required to pay the full amount before being provided access. If we are gathering the data for you, you will be requested to pay a portion of the fee prior to the start of gathering the data and the balance of the fee will be due prior to the data being provided to you.

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3. Orientation/Training

You are responsible for reviewing and understanding the research protocol. This information is available through a <u>powerpoint presentation</u>.

Copies of relevant Saskatchewan Cancer Agency policies will be provided to you to share with any student/affiliate working with you on your research.

4. Access to Electronic Systems

As an internal physician or other employee, if you are accessing our systems (i.e. Aria) yourself, you will be provided with a separate account and password to access patient information for the purposes of the project. This allows for auditing of access to patient information for research and other purposes. You may **not** access patient information with your normal clinical account.

5. Student/Affiliate Access to Data/Information

If you are bringing in a student/affiliate and he/she also requires access to our systems, he/she will be provided with a separate research account for their use only. This is the **only** way for them to access the information. They **must** read and sign a separate confidentiality form indicating their understanding and agreement of the information. You are also responsible, as the principal investigator, as per your research agreement, for ensuring they meet the requirements of the research agreement and confidentiality form.

6. Publication/Presentation/Release of Data/Information

When your project is complete, as per the agreement, you need to submit your draft presentation/publication via email to our coordinator (datarequest@saskcancer.ca) for review. Different specialists on the Data Access Committee (DAC) will review it and provide you with recommendations/suggestions for improvements. Although this is not an official approval of your publication/presentation, if something is noticed that seems incorrect we will connect with you to discuss. Once you have finalized your publication, we would appreciate a copy emailed to our coordinator so we can add it to our records and annual list of completed projects/publications.

7. Ethics Closure

When your project is complete, a copy of your closure letter from the Ethics Committee needs to be emailed to our coordinator (<u>datarequest@saskcancer.ca</u>).

8. Data Destruction/Return

After completion of your project, you need to connect with our coordinator via email (datarequest@saskcancer.ca) and follow a prescribed process for returning any data or ensuring its disclosure.