



IWK Research Registry Guidelines

These guidelines were developed to support approved researchers who wish to access the IWK Research Registry. The guidelines will be adjusted periodically. To ensure you are using the most recent version of the guidelines, please visit the IWK Research & Innovation Advancement website at <https://iwkhealth.ca/research/research-excellence/ways-participate>.

The following is a step by step guide for using the IWK Research Registry. Please note that each registry request is unique and therefore the process may need to be adjusted or modified on occasion.

Step 1: Complete IWK Research Registry Planning Form

The IWK Research Registry planning Form is available on the IWK Research & Innovation Advancement (RIA) website at <https://iwkhealth.ca/research/research-excellence/ways-participate> or on our [Pulse Forms page](#). This planning form is helpful in determining if the Registry is a good recruitment tool for your study. If you have any questions or concerns as you complete the planning form, please contact Joanne Street at Joanne.Street@iwk.nshealth.ca.

It is recommended that you contact the Team Lead Decision Support (currently Alexandra Banks) at Alexandra.Banks@iwk.nshealth.ca for assistance in determining the appropriate location codes to identify the study subjects you require.

Step 2: Consider the type of study

Feasibility? If you are accessing the registry to determine whether it is feasible to conduct a study (e.g. if there are sufficient numbers of patients available to participate), approval from the Research Ethics Board is not required and you may proceed to step 3.

Full study? If you are using the registry to recruit patients/families to participate in a research study, you will need to prepare and submit an application to the IWK Research Ethics Board and describe in detail how it will be used in your recruitment process.

Patient engagement? If you are accessing the registry to obtain contact information in order to invite patients/families to be part of the research team, contact us to determine the Research Ethics Board requirements.

Step 3: File an ICT Self-Service Request to request a report from the IWK Research Registry

To extract information from the Research Registry, complete the IWK Research Registry Planning Form and attach it to a completed [IT Self-Service request](#).

- *Service and Support → Applications and Software → Application Report/Data Analysis → Request Data Extract → Select App – type Meditech Magic ADM in the “Name” field and click OK.*
- Provide a description of the information you want to access and the REB ROMEO number in the Remarks section, and attach this Registry Planning Form and, if applicable, the REB approval letter to your request.

Please note: The time it takes for the IT Application support staff to prepare a report may vary from a week to several months depending on the complexity of the report, current work priorities and staff availability.

Step 4: Delivery of your IWK Research Registry Report

Once the report is completed and the ethics approval is confirmed, IT Application Support staff will send the report to you through a secure file transfer method. E.g. MoveIt or through another approved method if necessary.

Step 5: Use the report to contact patients by phone or mail

You will have 30 days (or longer if justification is provided to, and approved by, Research Ethics Board) to contact the patients/families by phone or mail to further screen for study suitability/interest in participation in the project.

Step 6: To have a patient removed from the IWK Research Registry

If you contact a person about a study and learn that the patient is deceased, or if a patient or family wants to be removed from the IWK Research Registry entirely, you must immediately notify IWK RIA at researchethicsIWK@iwk.nshealth.ca. The patient or substitute decision maker will be asked to provide: the full legal name, health card number and phone number of the person to be removed from the Registry. This will ensure the correct person is removed from the Registry and will ensure that they can be re-contacted if any issues arise. RIA will ensure that the Meditech record can be updated appropriately.

Step 7: Destroying your registry report

Patients/families should be contacted within 30 days of receiving their research registry contact list. Once this is complete, you must destroy the registry report in a confidential manner (e.g. deleting electronic files, shredding paper records).

If you have questions, require further consultation or need information, please contact: Joanne Street, Research Ethics Coordinator, at joanne.street@iwk.nshealth.ca