

# IWK RESEARCH REGISTRY - FAQ'S FOR PATIENTS

IWK Health is the leading children's and women's health centre in Maritime Canada. Our investment in research has led to many improvements in health care for women, children and families. The IWK research registry will continue to support this important work.

## What is the research registry?

The research registry is not a "thing" but rather a concept. The registry pulls data from the IWK health information system called Meditech. It does this to find patients who agreed to be contacted about joining approved IWK research studies. When you register with the IWK, registration staff will ask you if you want to join the research registry and note your answer directly on your IWK patient health record. IWK researchers who have received approval for their study from the Research Ethics Board could then access names from the registry in order to contact patients to see if they are eligible and/or interested in taking part in a specific research study at the IWK.

## How does the research registry work?

The research registry is a way for approved researchers to access limited personal health information about IWK patients who have agreed to be contacted for future research studies. This basic information includes:

- name, address, phone number
- date of birth and gender
- The health condition or reason you attended the IWK and/or the clinic you visited
- This includes the current visit and health reason for the visit, previous visits and the health reason for those visits and any future health conditions and related visits to the IWK.

## How do I join the research registry?

All patients registered at the IWK can join the research registry. IWK registration staff will ask you if you want to join the registry when you register at the IWK. If you agree to join the registry, (e.g. if you agree that IWK researchers can contact you about approved research studies in the future), this will be noted on your IWK

health record.

### What will the registration staff ask me?

When you register at the IWK, staff will say ... *“The IWK has a Research registry for patients who might be interested in being contacted about participation in approved research studies at some point in the future. You/your child’s contact information and limited personal health information (for example, demographics and any health conditions) would be made available to researchers so they can assess whether you might be eligible for a study and contact you. Would you like to be included?”* You will also be offered a brochure about the research registry.

### Can my friends and family members join the research registry?

For now, only patients registered at the IWK can join the registry. However, there are many IWK research studies that people can take part in without joining the registry. To find out about current studies, visit the Research & Innovation Advancement website (<https://iwkhealth.ca/research/research-excellence/active-research-areas>) or the Canadian Centre for Vaccinology website (<http://www.centerforvaccinology.ca/participate-in-a-study/current-studies/>).

### What happens if I am contacted for a study?

If you join the IWK research registry and are a potential candidate for a study, an IWK researcher who has received approval for his/her study from the Research Ethics Board may contact you either by phone or mail. The researcher will explain the study to you and may ask you a few questions to see if you are eligible to take part. If you are a good candidate for the study, they may invite you to take part or suggest that you contact them if you are interested in taking part. It is completely up to you to decide if you want to take part in the study. Whatever you choose, it will not change the quality of care that you receive at the IWK.

### How do I withdraw from the research registry?

Once you join, you will stay in the research registry unless you choose to withdraw. If you want to withdraw from the research registry, please contact Research & Innovation Advancement (RIA) at IWK Health. You will ask to have your name removed from the Research Registry. The IWK RIA staff person will ask you for your full legal name and health card number to ensure that the correct

person is being removed from the registry.

### Will my information be kept private?

Yes. Your contact and personal information will be kept confidential, secure, and protected. Researchers will not be permitted to access the registry directly. Rather, certain limited information about patients who have consented to be part of the registry will be pulled from the electronic system and put into a report that will be delivered to the researcher in a secure format. This information includes: name, address, phone number, date of birth, gender, name of clinic(s) you attended, and/or reason for your visit to the IWK (past, present and future). The information provided to the researcher will be limited to that approved by the Research Ethics Board.

### I have been an IWK patient in the past, but am not currently a patient – can I still join the research registry?

Yes, if you are currently a patient, or if you have been a patient at the IWK in the past, you can contact RIA and ask to be added to the research registry. You will be asked for your full legal name, phone number and health card number.

### If I do not want to join the research registry, will this affect my health care?

No, participation in the research registry is entirely voluntary. Your participation will not affect the care you receive at the IWK now, or in the future.

### How long will I remain in the research registry?

Once you join the research registry, you remain a part of it until you choose to withdraw. You can withdraw from the research registry at any time by contacting RIA.

### How often will I be contacted by researchers?

Because the research registry is new, it is difficult to predict how often you might be contacted. Some people may be contacted more often than others. When a researcher contacts you, if you are not interested in participating in a study, you can simply say “no thanks” and you will still remain in the registry. If you wish to withdraw from the registry, contact RIA and ask to be removed.

Who do I contact with questions or to withdraw from the research registry?

**IWK Research & Innovation Advancement (RIA)**

Tel: (902) 478-5096

E-mail: **ResearchEthicsIWK@iwk.nshealth.ca**

Website: **<https://iwkhealth.ca/research/research-excellence/ways-participate>**