

### **FAQ for research participants: Research Registry and Medical Record Number**

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Beginning April 13, 2026, Holland Bloorview Kids Rehabilitation Hospital (Holland Bloorview) will introduce a new registry to better understand who is participating in research. We will assign each research participant a unique identifier known as a **medical record number** (MRN). This will enable us to learn about research participation at Holland Bloorview.

This research registry will help us understand who participates in research. It will also help us discover new ways to support research participation and make sure everyone has the opportunity to take part in research at Holland Bloorview.

Here is a list of frequently asked questions about our research registration process and MRNs so you have all the information you need. Contact your research study coordinator if you have any questions about this process.

#### **1. What is the new research registry?**

The research registry is a secure database that stores basic demographic and socio demographic information about all participants, as well as what studies they participate in and when.

#### **2. What is the process to get registered?**

Holland Bloorview will:

- enroll current and new research participants into the new research registry,
- assign each research participant an MRN; and
- ask each participant to complete a short online survey.

#### **3. Why is Holland Bloorview making these changes?**

Creating an MRN and research registry is a standard way to track and understand who is participating in research at the hospital. We use this confidential and secure information for hospital operations and governance purposes.

By understanding who is participating in research, Holland Bloorview can advance new health discoveries and innovations. This also helps researchers make sure their recruitment efforts reflect the populations who could potentially benefit from Bloorview Research Institute (BRI) research.

#### **4. How and where will this information be stored?**

Information in the research registry will be safely stored on our secure hospital systems and protected by institutional safeguards. Only authorized staff who need this information to perform their duties can access it. Their access is checked regularly under the hospital's security policies.

### Medical Record Number

**1. What is a medical record number (MRN)?**

An MRN is a unique hospital number. This number is created through our electronic health record system called Meditech. This system is used to securely track and manage all client and research participants across the hospital.

**2. What if I am already a client at the hospital or become one at a later date? Will I get a different MRN number?**

No, you will only be assigned one MRN. The MRN will be used for clinical care and the research registry.

**3. When will the MRN number be created?**

For research participants who are not already Holland Bloorview clients: once you consent to be part of a research study, the study team will collect basic demographic information from you. This information will be shared with designated hospital staff who will create the MRN number in Meditech.

**4. What information about me will be stored in the electronic health record system?**

If you are a research participant, only your basic demographic information (name, date of birth, sex at birth, address, phone number and date of first study visit) will be stored in our electronic health record system.

If you are a client, this information, plus your health information will be stored in the system.

**5. I am a client at Holland Bloorview. Will my clinical team know that I am participating in research because I have an MRN?**

No. Your research information and clinical information will be kept separate. Therefore, clinical teams will not see your research information and research teams will not see your clinical information.

**6. Can I ask to have my MRN number deleted?**

No. Once an MRN number is created, by law, we have to keep it in our electronic health record system.

## Research Registry

### 7. What is the research registry?

The research registry is a secure database. This database stores information about people who are taking part in research at Holland Bloorview.

### 8. What information will be stored in the research registry?

The registry will contain your name, MRN number, address, date of birth, sex at birth, phone number, the study(s) you participate in and the date of each study visit.

It will not include any information you share during your research study visit.

### 9. Who can see my information in this registry?

Only designated hospital staff will have access to your information in the registry.

### 10. Can I withdraw from the registry?

Your basic information, including your name, MRN number, address, date of birth, sex at birth, phone number and date of first study visit cannot be removed from the research registry. But you can ask for the specific studies you have participated in and the dates you participated to be removed at anytime. Just email [brirequests@hollandbloorview.ca](mailto:brirequests@hollandbloorview.ca) to ask for your information to be removed from the registry.