

myUHN Patient Portal

Frequently Asked Questions (FAQ): Research Activities and Participation Preferences

1. Why is the hospital involved in research?

University Health Network (UHN) is dedicated to conducting research to generate new scientific knowledge, build cutting-edge technology, and lead health innovation. Research is part of all aspects of UHN. Many of our physicians are leading scientific experts in their field, and our research staff works directly with your healthcare team. To learn more about research at UHN watch this **What is Research?** video.

2. Why do you need my permission for research staff to contact me?

Ontario privacy law states that in order for a research team member to directly contact you about a research study, someone who is directly providing you with healthcare must first obtain your permission for that research contact. Research team members will only access your contact information and relevant Personal Health Information with your permission. Here is a link to UHN's Privacy Policy which explains the rules for using and collecting your health information: **UHN Privacy Policy**

3. How can I find out about research activities I may be interested in participating in at UHN?

Patients have the opportunity to participate in a research study, or work with our research staff as a patient partner. You may learn about or get involved in these research activities at UHN in the following ways:

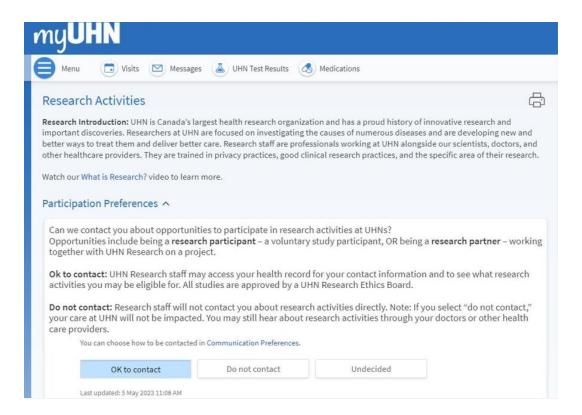
- 1) You may respond to an advertisement within the hospital or online about a specific research activity and contact the research team directly; or
- 2) Your doctor or other healthcare provider may ask if you would like to learn more about a research study that you may be eligible for; or
- 3) You may be approached by a UHN research team member, who is not your doctor or healthcare provider, about a particular research activity if you have given us your permission to do so. See the information below about how you can provide this permission to a researcher by indicating you are "OK to Contact".



4. How can I give my permission for UHN research staff to contact me directly about a research activity?

You can give your permission to be contacted about research to your healthcare provider or administrative staff when you are having a hospital appointment. Also, you can follow these steps to give your permission through your myUHN Patient Portal:

- Log into your myUHN Patient Portal through:
 - o www.myuhn.ca
 - OR, the myUHN app (myChart app). Watch this <u>video</u> on how to download the app.
- Find "Menu" in the top left corner of your screen and click on it.
- Under the "Resources" heading, click on "Research Studies" (OR in the "Search the menu" box, type "research" and click on "Research Studies").
- Beside "Participation Preferences", click the arrow on the right to see the options
- Select one of the options:
 - o "OK to contact"
 - o "Do not contact"
 - o "Undecided"





5. What does it mean if I select "OK to contact"

Selecting "OK to contact" means you are providing permission for a qualified member of a UHN research team to:

- access your medical chart to review limited information (such as your medical history, medication list, or other research studies you are participating in) to determine if you may be eligible for a research opportunity
- contact you to give you information about a research opportunity

Selecting "OK to Contact" does NOT mean:

- you are guaranteed to be contacted for research
- research teams have unlimited access to all your Personal Health Information.
- you give your consent to participate in any research activity or for your data to be used for research

Once you receive all the information you need about the research activity, you will be the one who makes the decision about participating in a research activity. Your decision about participation in research will not affect the level of care you receive at UHN.

6. What does it mean if I select "Do not contact"

Selecting "Do not contact" means research staff will not access your medical chart or contact you directly about research activities.

Please note, you may still hear about research activities through your doctors and healthcare providers.

Also, if you have previously given specific research teams permission to contact you, those research staff may still access your medical chart to determine your eligibility and contact you to provide information about a research opportunity.

7. How will research staff communicate with me to tell me about research opportunities?

If you have selected "OK to Contact" research teams may contact you to provide information about research opportunities by:

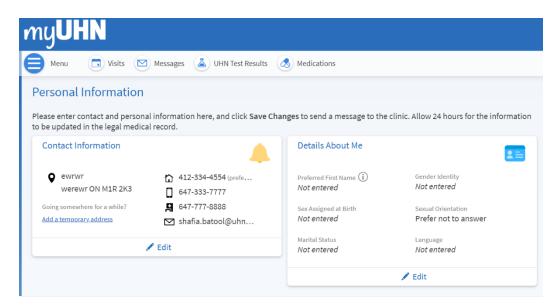
- approaching you in-person, during your next clinic appointment or admission at the hospital; or
- calling you; or
- emailing you, if you have given permission to be contacted by email.



8. How can I update my contact information to receive information about research opportunities?

<u>Watch this video</u> or follow the steps below to update your contact information (such as your mobile phone number, mailing address, email address, etc.).

- Log into your myUHN Patient Portal at: www.myuhn.ca
- Find "Menu" in the top left corner of your screen and click on it
- Under the "Account Settings" heading, click on "Personal Information"
- In the "Contact Information" section, click the "Edit" button (at the bottom of the section)
- Click on the field you want to update and enter your information
- Click "save changes" on the bottom when you are done

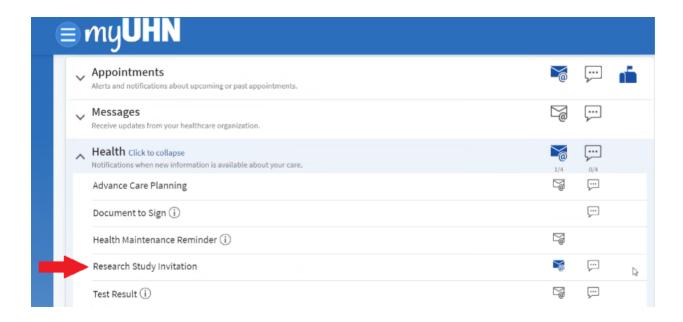


You can choose to turn on, or turn off, notifications from your myUHN account about research study invitations by:

- Logging into your myUHN Patient Portal at: www.myuhn.ca
- Find "Menu" in the top left corner of your screen and click on it
- Under the "Account Settings" heading, click on "Communication Preferences"
- Beside the "Health" heading, click the arrow on the left to see the list of options
- To the right of "Research Study Invitation", click on the email and/or text icon
 - The icon will be highlighted in blue when it's selected. A white icon means you have not selected this method of communication.

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9. Once I give my permission to being contacted for research opportunities, can I change my mind?

Yes, you can change your permission to being contacted for research activities at any time. To make this change:

- Follow step #3 outlined above to log into your myUHN Patient Portal and navigate to "Participation Preferences" and select the option that best suits you
- Or, at your next clinic visit, tell your doctor or healthcare provider to update your research contact permission in your medical chart

10. Who is a qualified member of a research team?

A qualified member of a UHN research team may be

- a physician or healthcare provider (e.g., nurse practitioner); or
- a scientist or research coordinator; or
- in some cases, university students who are working on a research study.

These research team members undergo training in research ethics, patient safety and privacy, and good clinical research practices.

Many of these research team members are part of your clinical care team or work directly with your clinical care team to bring research opportunities directly to patients.



11. Who has access to my personal health information for the purpose of research?

Your medical records at UHN are confidential. UHN has measures in place to safeguard your privacy and restrict access to your medical records to members of your care team.

A qualified member of a UHN research team may look at limited information in your medical records when:

- 1) you select "OK to Contact" in your myUHN Patient Portal; or
- 2) you give your permission to be contacted about research to your healthcare provider or administrative staff at the hospital.

Research staff access this limited information only to see if you would be eligible for a research activity and to communicate with you about the research opportunity.

12. Where can I learn more about giving permission for research staff to contact me?

To learn more about participating in research or provide feedback, contact:

 the Pride In Patient Engagement in Research (PIPER) Team at: Emailpiper@uhn.ca | Phone- 416-597-3422 x 7673 | Website: www.kiteuhn.com/piper

For questions or help with using myUHN, contact:

• the myUHN Patient Portal Team at: **Email**- myUHN@uhn.ca | **Phone**- 416 340 3777 | **Website**: www.uhn.ca/PatientsFamilies/myUHN