How-To Guide for Using the OncoQuebec Website

The Jewish General Hospital's Patient and Family Resource Centre

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Welcome

Welcome! This guide was made to help you understand the OncoQuebec website (https://oncoquebec.com). This guide includes important information about cancer-related clinical trials in Quebec. It will also help you use the filters on the website and help you find the best clinical trial for you or your loved one's disease.

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What is OncoQuebec?

OncoQuebec is a website that groups together all of the cancer clinical trials in the province of Quebec. There are many different kinds of clinical trials on the OncoQuebec website. They have been grouped together by the type of cancer and the type of treatment. The clinical trials are either currently open or opening soon. The hospitals that are participating in the clinical trials are all part of the Quebec Clinical Research Organization in Cancer (Q-CROC) network.

Location

We understand that location matters; you might feel more comfortable at your local hospital, or you might be willing to travel for the purposes of participating in the clinical trial. Not every hospital participates in clinical trials. Some of the hospitals that do participate (16 hospitals across 8 cities in Quebec) are part of the Quebec Clinical Research Organization in Cancer (Q-CROC). The OncoQuebec website lets you see only the clinical trials in your hospital or city of choice and hides the rest.

Participating Hospitals

1. Centre Hospitalier de l'université de Montréal (CHUM), Montreal
2. Centre Hospitalier de l'université de Sherbrooke, Sherbrooke
3. Centre Hospitalier de Québec, Laval University
4. Centre Hospitalier Universitaire de Sainte-Justine, Montreal
5. CISSS of Bas-Saint-Laurent, Rimouski
6. CISSS of Outaouais, Gatineau
7. Cité-de-la-Santé Hospital, Laval
8. CIUSSS of Mauricie and Central Quebec, Trois Rivières
9. Jewish General Hospital, Montreal
10. Maisonneuve Rosemont Hospital, Montreal
11. McGill University Health Centre, Paediatric and Adults, Montreal
12. Sacré Coeur Hospital, Montreal
13. Saguenay–Lac-Saint-Jean Hospital, Chicoutimi
14. University Institute of Cardiology and Respirology of Quebec, Laval
15. CISSS de la Montérégie centres, Charles LeMoyne hospital, Montreal
16. CIUSSS de l'Ouest-de-l'Île-de-Montréal, St-Mary's hospital, Montreal

Cities

Chicoutimi
Gatineau
Laval
Montreal
Quebec
Rimouski
Sherbrooke
Trois Rivières

Website

The OncoQuebec website can be found at the following web address:
https://oncoquebec.com/en
The website can be difficult to navigate and some of the language used is complicated. At any time, you can consult the glossary on page 13 to get definitions to some of the words and terms used on the website.
The main page of the website shows you a search box where you can type in your cancer, city or the keywords that are important for your disease or situation. If you don't know what you're looking for, you can use the filters that the website provides.
There are numbers under the search bar. These numbers will change depending on the number of clinical trials there are on the site, the number of researchers, the number of hospitals, and the number of cities.

Main Filters

Tumor Site & Hospital

Filters are used to include or exclude certain information and allow you to find clinical trials that match what you're looking for. There are two main filters on the homepage of the OncoQuebec website. You can filter by **tumor site** or by the **hospital.** The tumor site refers to where the cancer is located in your body or the type of cancer you have.

If you choose to look for trials by tumor site, you will have to pick from a list. Each category will have the number of trials that are looking for patients (recruiting), the number of trials that will be opening soon, and the number of trials that are for children (pediatric). Here is an example of what the website has on hematological (blood) cancer. In this example, 108 clinical trials are looking for patients to participate, 5 clinical trials are opening soon, and 39 clinical trials involve children:

These are the tumor site options available:

Endocrine: Cancers that begin in glands that produce hormones, such as thyroid cancer.

Gastrointestinal: Cancer of the stomach,
esophagus, colon, rectum, pancreas, liver and biliary tract.

Genitourinary: Cancer of the bladder, kidneys, urethra, and prostate.

Symptom management: Clinical trials are not for specific types of cancer. Rather, these are trials that focus on helping patients to cope with the unpleasant side effects of their symptoms or the side effects of specific treatments such as chemotherapy.

Gynecologic: Cancer of the ovaries, cervix, vulva, vagina, and uterus.

Hematological: Blood cancers, such as leukemia, lymphoma and multiple myeloma.

Lung cancer: Cancer of the lungs such as small cell lung cancer, non-small cell lung cancer.

Neurological: Cancer of the brain and spinal cord.

Melanoma and skin: Cancer of the skin.

Sarcoma: Cancers of connective tissues in the body, such as your bones, muscles, tendons, cartilage.

Breast Cancer: Cancer of the breast.

Head & Neck: Cancers that start in the mouth, nose, throat, larynx, sinuses or salivary glands.

Solid Tumor: Cancers in your organs, muscles or bones.

Other: Clinical trials that are for several types of cancers.

You can also choose to look for clinical trials by the hospital. The 14 hospitals that are mentioned on page 3 will be available to click on.

Other Filters

It is possible to get even more specific with your search. Once you have already filtered by the hospital or the tumor site, you can click on "**More Filters**" to see more options. These options include the disease, the investigator (this is the doctor who is in charge of the clinical trial), the city, the disease stage, and the treatment type. You can select more than one filter at the same time.

Disease Stage

The stage of your cancer refers to the size of cancer and how far it's spread. When you are diagnosed, your doctor will tell you what stage of cancer you have. Usually, the stages are between 1 and 4. The OncoQuebec website does not use the same system and can sometimes group together different stages of cancer. Here are the categories that you will see on the website:

Early cancer

Cancer that is early in its growth and may not have spread to other parts of the body.

Advanced cancer

Cancer that is unlikely to be cured or controlled with treatment. This refers to cancer that may have spread from where it first started to nearby tissue, lymph nodes or parts of the body. Clinical trials for this stage of cancer will be for treatment that may help to shrink the tumor, slow the growth of the cancer cells or provide relief from symptoms.

Metastatic cancer

Cancer that has spread from the place where it started (primary site) to other places in the body (secondary site).

Relapsed/Recurrent/Refractory cancer

These stages are grouped together because they have similar meanings.

Relapsed cancer

The return of a disease or the symptoms after a period of improvement.

Recurrent cancer

Cancer that has come back (recurred) usually after a period of time when the cancer could not be seen. It may come back to the same place or another place in the body.

Refractory cancer

Cancer that has not responded to treatment. Sometimes it is called resistant cancer. This applies to cancer that became resistant at the beginning or during treatment.

The website also groups together categories to show that some clinical trials will accept different disease stages:

Any stage

Clinical trials for people with any of the disease stages mentioned above.

Early or Advanced cancer

Advanced or Metastatic cancer

Treatment Type

The treatment type filter will show you what kind of therapy you will be treated with during the clinical trial. Here are the categories that you will see on the website:

Chemotherapy

This is a treatment that may be given by mouth, by injection or infusion or on the skin. It stops the growth of cancer cells either by killing them or stopping them from dividing. It can be given alone or with other treatments.

Hormone therapy

This is a treatment that may be given by mouth or injection. Synthetic hormones or other drugs may be given to block the body's natural hormones in order to slow or stop the growth of cancer cells. Sometimes, surgery is needed to remove the gland that makes a certain hormone.

Radiation Therapy

This is a treatment that may come from a machine outside the body (external-beam radiation therapy) or from radioactive material placed near cancer cells in the body (internal radiation therapy or brachytherapy). Radiation therapy can also be systemic, meaning patients are given a radioactive substance that travels in the blood to tissues all over the body. It is used to kill cancer cells and shrink tumors.

Targeted Therapy

This is a type of treatment that uses drugs or other substances to identify and attack specific types of cancer cells with less harm to normal cells. It works by targeting changes in cancer cells that help them grow, divide and spread. They do this by interfering with specific molecules (molecular targets) which are involved in the growth, progression and spread of cancer. There are big differences between targeted therapy and

chemotherapy. Most chemotherapies work on all cells, both normal and cancerous.

Targeted therapies are chosen or made to work with a specific target. Chemotherapy kills cancer cells, but targeted therapy blocks the growth and spread of cancer cells. There are several types of targeted therapy such as monoclonal antibodies (see Immunotherapy) or inhibitors.

Immunotherapy
This treatment is a type of biological therapy that uses the body's own immune system to fight cancer. Immunotherapy may be given by mouth, injection or infusion or on the skin. There are several types of immunotherapy. These are the therapies that are included:

- Immune checkpoint inhibitors
- T-cell transfer therapy
- Monoclonal antibodies

Electric Fields or Tumor Treating Fields (TTF)
Tumor Treating Fields (TTF) is a new type of electromagnetic field treatment for glioblastoma. It is not invasive. This means that there are no cuts to your body and nothing is placed inside it. There is a device called **Optune**, which is attached to the patient's shaved head using adhesive patches that hold insulated ceramic disks. These disks are attached by wires to a portable battery-powered device that is carried in a shoulder bag or backpack. Optune can also be attached to a power supply. When turned on, the device creates low-intensity electrical fields which slow or stop glioblastoma tumor cells from dividing and may destroy them.

Other
This category refers to treatments that are not specifically targeting cancer and are being used to treat cancer or the symptoms it causes.

Combinations
The OncoQuebec site groups together the clinical trials that use more than one type of treatment. Here are the categories that you will see on the website:

- **Chemo + Radiation Therapy**
- **Chemotherapy + Immunotherapy**

- **Chemotherapy + Targeted therapy**
- **Radiation Therapy + Targeted Therapy**
- **Immunotherapy + Targeted therapy**

*For more information about all these therapies, please speak with your doctor or the contact person for the study.

Study Page

Once you have found and clicked on the clinical trial you are interested in, you will be taken to that clinical trial's webpage. Here you will find important information about the clinical trial and the team that is running it.

The main information will be shown. This will include the category, the official title of the clinical trial, the investigator and the hospital or health center. Example:

You will also see information about the disease type, stage, treatment type, and line. Information about the phase of the study will also be displayed here. For more information about the study phases, please see the glossary on page 19

Under the "I**nformation**" tab, you will find details about the study, as well as the inclusion and exclusion criteria. For more information about the inclusion and exclusion criteria, please see the glossary on page 19.

The hospitals that are participating in the clinical trial will be shown on the right- hand side of the webpage. There can be more than one hospital involved in the clinical trial. The first hospital under "Participating Hospitals" is where the principal investigator works. Other hospitals that are also recruiting patients will be shown under "More Hospitals"

If you would like more information about the clinical trial, the best people to contact are the ones that are directly involved. To get their information, click on the "Contact" button. You will find the information for the principal investigator and the for the study team.

ClinicalTrials.gov

At the bottom of the study page, you will see this section called “More information.” You can click on the code that is in grey below.

This link will take you to the clinical trial’s page on the U.S. National Library of Medicine’s **ClinicalTrials.gov**. This website groups together clinical trials from the United States and around the world and offers more information about them. You can find more details about the clinical trial you’re interested in on this website but, keep in mind, this website uses complex language and terms that you might not be able to understand. It is important to always consult your doctor or the clinical trial team if you do not understand something and need more information.

On the website, words that are underlined (like in the picture) can be clicked on for more information and a formal definition.

A glossary window will pop-up on the right-hand side of the screen. You will see the definition for the word that you clicked on and will be able to search for other terms. If you leave the search box blank, all the terms in the glossary will be available to you.

Glossary of Terms

Accepts Healthy Volunteers: A clinical trial that accepts volunteers who do not have the disease that is being studied.

Adverse Event: A change (positive or negative) in the health of a patient participating in a clinical trial that may or may not be related to the treatment studied.

Arm: A group of participants in the clinical trial. Depending on the study, this group can receive the treatment or not.

Baseline Characteristics: Information that is collected from the participants before the study begins. Can include personal information such as age, gender, ethnicity, etc.

Blinded Study: In this study, one or more groups of participants don't know which treatment they are receiving. The participants can receive the drug that is being tested OR a placebo. (see also: masking)

Clinical Study/Trial: A research study involving volunteers (also called participants) that is intended to add to medical knowledge.

Collaborator: Someone other than the researchers who provides support to the study. For example, someone who provides the funding necessary to complete the study would be a collaborator.

Control Group: The participants in this group do not get the treatment that is being studied in the trial.

Diagnostic Trial: A study that looks into the tests or procedures for diagnosing a disease.

Eligibility Criteria: Things that are required from the volunteers in order to be selected for the study OR things that exclude the volunteers from participating in the study.

Enrollment: The number of participants in a clinical study. The estimated enrollment is the number of participants needed for the study.

Exclusion Criteria: A kind of eligibility criteria. These are reasons that a person is not allowed to participate in a clinical study (ex: too young, too old, male, female, previous medication, etc.)

Expanded Access: A way for patients with serious diseases or conditions

who cannot participate in a clinical trial to get the treatment, even though it has not been approved yet. Also called compassionate use.

Experimental Group: The participants in this group get the treatment that is being studied in the trial.
The Food and Drug Administration (FDA): An agency in the United States that is in charge of protecting public health. They make sure that all new medications, treatments, devices and vaccines are safe.

Health Canada: An agency is Canada that is in charge of protecting public health. They make sure that all new medications, treatments, devices and vaccines are safe.

Inclusion Criteria: A type of eligibility criteria. These are the reasons that a person is allowed to participate in a clinical study.

Informed Consent: Before agreeing (or consenting) to be a part of a clinical trial, you must make sure that you understand all the risks and benefits. You will be given all the important information about the study by your doctor and should tell him/her if you have any questions or concerns. When you are comfortable and feel that you have all the information necessary, you can sign the consent form and participate in the study.

Intervention/Treatment: This is what the researchers are testing in the study. It could be a medication, a device, a vaccine or a test. An intervention doesn't have to be medical. It could also be exercise, changes to diet or education.

Investigator (Primary): The person who is in charge of and leads the study.

Masking: When the researchers in the study OR the participants do not know which participant has been given the treatment or the placebo.

Participant: A person that has been selected to take part in the clinical trial.

Phases: These are the steps that a clinical trial goes through. Information

from one phase is collected and used to make the next phase better.

Different phases are used for different things.

Phase 1: This phase tests how safe a treatment is and what the best dose is.
Phase 2: Now the best dose has been established, this phase is used to see how well a treatment works for a certain disease. Safety and side effects are further evaluated.

Phase 3: This phase is used to compare the usual treatment for a disease to the new one that is being tested. Researchers want to know if the treatment they are testing is better than the one that is usually used. The data from Phase III trials is often needed for the FDA to approve the use of the drug tested in the general public.

Phase 4: The aim of this phase is to test new drugs approved by the FDA. Researchers gather information about the short-lived and long-lasting side effects of the treatment.

Placebo: Also called sugar pill. It looks the same as the drug that is being tested, but it does not contain any medication.

Prevention Trial: A study looking for a way to avoid a disease.

Primary Outcome Measure: This is what the researchers are most hoping will happen as a result of the treatment/intervention (ex: remission, symptom control, improved quality of life, etc.).

Protocol: The description and the instructions of a clinical study. It will describe why the study is being done, how it will be done, how many people will be included, how long it will last, what treatments or tests you will get, and what information doctors and researchers will collect from you. The protocol may sometimes offer background information and statistics about the disease.

Randomized Allocation: Participants are randomly assigned to different groups of the clinical trial.

Recruitment: Being recruited to participate in a clinical trial means that you meet the list of requirements to participate and you have decided to participate in the clinical trial. Recruitment for a clinical trial is the process of approaching participants to take part in the clinical trial and getting their consent to participate.

Recruitment Status:

- **Not yet recruiting:** The study has not started selecting participants.
- **Recruiting:** The study has started and is currently selecting participants.
- **Enrolling by invitation**: The study is selecting its participants from a group of people decided on by the researchers in advance. These studies are not open to everyone who meets the eligibility criteria. Instead, participants must be invited by the researchers.
- **Active, not recruiting:** The study is ongoing, and participants are receiving an intervention or being examined, but potential participants are not currently being recruited or enrolled.
- **Suspended:** The study has stopped early but may start again.
- **Terminated:** The study has stopped early and will not start again.

  Participants are no longer being treated or evaluated.
- **Completed:** The study has ended normally, and participants are no longer being treated or evaluated. In this case, the last participant's last visit with the researchers and team has taken place.
- **Withdrawn:** The study stopped early, before selecting the first participant.

Registry: This is a kind of observational study. Researchers leading this study are interested in collecting information about patients' diseases and treatments. This helps researchers understand how conditions or treatments affect people.

Research Ethics Board: A group of doctors, scientists, advocates, researchers, ethics specialists and members of the community that has been assigned to review and follow the clinical study. They discuss the ethical implications as the study and are there to make sure that the participants are safe. Also known as an Institutional Review Board (IRB), an Independent Ethics Committee (IEC) and an Ethical Review Board (ERB).

Screening Trial: A study looking for a way to identify diseases.

Secondary Outcome Measures: These are outcomes the researchers are hoping for as a result of the treatment/intervention. There is usually more than one and they are not as important as the primary outcome measure.

Study Type:

- **Interventional**: A type of study where participants receive one or more interventions so that the researchers can evaluate the effects. Participants may receive diagnostic, therapeutic, or other types of interventions. Also called experimental studies.
- **Observational:** A type of study where participants are not given an intervention or treatment. Instead, participants are observed in their everyday lives, using the interventions or treatments that they would normally use.

Sponsor: An individual, company, institution or organization that is responsible for ensuring that the clinical study is conducted in accordance with the protocol, the relevant regulatory requirements and Good Clinical Practice. They are responsible for setting up the trial, managing it and/or financing the clinical trial.

Treatment Trial: A study testing new kinds of treatments. The treatments can be in the form of medicine or a device.

Withdrawing your Consent: Your participation in the clinical trial is voluntary and you may choose to stop at any time. Speak to your doctor or the person in charge of the study if you have any concerns and want to stop the clinical trial.

Remember: If you have any questions about this document, you can contact the Patient Education Librarian. If you have any **medical questions**, speak to your doctor / medical team.

QUESTIONS / NOTES