

Participate in COVID-19 Research

Category: 4. Next Steps

Why should you participate in Long COVID research?

Since Long COVID is a relatively new condition, research is especially important and everyone's contributions are valuable. When there are diverse people participating in research, this supports the growth of knowledge that reflects the community we live in.

Here are some other reasons why you might want to participate in Long COVID research:

- Helping others with Long COVID by sharing information about your condition and providing feedback about the care and services you received
- Learning more about your condition to help you with your own recovery journey
- A chance to feel validated by sharing your experience of Long COVID
- Getting free access to new treatments and support services that may help you

A chance to interact with doctors and other research team members who are passionate about your condition.



POST-COVID-19
Interdisciplinary Clinical Care Network
Provincial Health Services Authority

Who can participate in Long COVID research?

Each research study has specific requirements regarding who they would like to include. This is often called the “eligibility criteria” or “inclusion criteria.”

Some studies do not require in-person visits and you can participate over the phone or computer.

Most Long COVID research studies are interested in recruiting patients who have or have had Long COVID. However, many studies also require other participants to act as “controls” whose results can be compared with the Long COVID patients. For example, people who have not had COVID-19 or those who had COVID-19 but not Long COVID.

Some studies are also interested in learning from the caregivers of patients with Long COVID.

What types of research studies can I participate in?

There are two main types of health research studies that are conducted for Long COVID:

1. Interventional studies

These studies involve trying out something new for Long COVID that researchers think could be helpful but has not yet been proven. This could be a treatment such as a medication or new support program.

A common type of interventional study is a randomized control trial (RCT). In an RCT, participants are randomized to one treatment or another and sometimes do not know which treatment they are receiving (they are “blinded”). Participants are followed very closely for side effects and the studies are not allowed to continue if the treatment is found to be harmful. Participants are usually compensated for their participation and may benefit from receiving the new treatment.

2. Observational studies

In these studies, you are not asked to try anything new, but researchers collect information from you to learn more about your condition. This may involve providing blood samples, undergoing tests, completing questionnaires, or participating in an interview. Participants are usually compensated for their participation.

Where can I find out more information about Long COVID research studies?

There are multiple researchers in Canada who are conducting Long COVID research. Below are examples of ways you can find out more about getting involved.

Long COVID Web

Long COVID web maintains a list of various studies from across Canada that are actively recruiting participants. Each study will have its own set of requirements for participants. Learn more on [the Research Engagement page](#).

Patient-Led Research Collaborative

[Patient-Led Research Collaborative](#) is led by people with Long COVID and other associated illnesses (like myalgic encephalomyelitis/chronic fatigue syndrome, or ME/CFS for short, and postural orthostatic tachycardia syndrome, or POTS for short) who are also researchers. The website contains information and resources for people with long COVID, for clinicians, for researchers, and for the general public.

Long Covid Studies

[Long Covid Studies](#) is a web platform about current clinical trials and how to participate. It was developed by a patient with lived experience of Long COVID to simplify access to information about clinical trials and how to enroll in relevant studies.

The information on this site draws from the two major clinical trials databases that include all registered Canadian trials: www.clinicaltrials.gov and <https://health-products.canada.ca/ctdb-bdec/?lang=eng>

REACH BC

If you live in British Columbia, REACH BC is a website that connects the general public with researchers. Sign up by visiting www.reachbc.ca, clicking on the “Sign Up” button, and creating a volunteer profile. You will be contacted when there is a study looking for participants like you. On the REACH BC website, under the “Find Studies” tab, you can also browse through a directory of ongoing studies in B.C. and contact the research teams directly.

When do I find out the results of the research studies?

It often takes a long time (sometimes several years) before the results of a research study can be shared with the public. If you are interested in being contacted when the results are available, you should ask the research team when you enroll.