

# The Canadian Respiratory Research Network Long COVID-19 Study

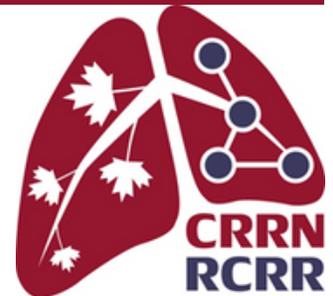
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Canadian Respiratory Research Network -  
Researchers Annual Meeting 2017

## Background

The Canadian Respiratory Research Network (CRRN) is a national research network established in 2014 which brings together researchers from across Canada to work together in a coordinated fashion in order to improve understanding and treatment of asthma and COPD, the two most important chronic airway diseases in Canada.



## CRRN Long COVID-19 study

The CRRN researchers applied and received a grant from the Canadian Institutes of Health Research to study how and in what way COVID-19 impacts the lungs, and why some people are affected and others are not.

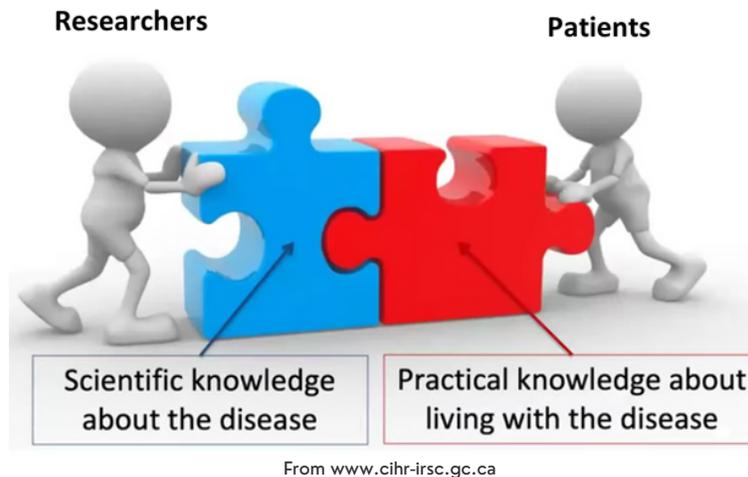
They plan to study a large national representative sample of people with COVID-19—some who needed hospitalization but most who did not. Through telephone questionnaires, they will determine their respiratory symptom burden, quality of life and medical history. The CRRN team will invite random patients with either high or low burden of disease, as well as patients who were infected with different COVID variants, to one of our 12 Canadian testing centres where they will compare the results of in depth breathings tests, imaging and bloodwork to understand how the virus differentially affected their lungs. They will also do immunological and inflammatory testing to understand why some people suffered lung damage and others did not.

The information CRRN collects and analyze will help patients and health care providers understand how and why COVID affects the lungs and how it should be treated. It will also reveal how different COVID variants affect the lungs. The researchers will use this new knowledge to write a formal guide on what respiratory monitoring and testing should be done after COVID-19 infection. This will ensure that people affected by COVID get the care they need to maintain lung health.

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# Patient/Caregiver Advisory Group

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We wish to involve individuals with persistent symptoms after a COVID-19 infection and health and social care caregivers that work with ethno-cultural community and underrepresented populations. It is expected that meetings will take place every 3 months and will last for approximately 1 hour.

Members of the Advisory Group are expected to take an active part in the group meetings. The main duties involve reading a small amount of material sent prior to each meeting and being prepared to discuss issues arising. We are particularly interested in your lived experiences or those caring with individuals with persistent COVID-19 symptoms.

**Video:** [COVID-19 - What is being a patient partner?](#)

## Main responsibilities

1. To attend advisory group meetings approximately once every 3 months. These will be held virtually or by phone.
2. To read material sent to you prior to each meeting. This may include minutes of previous meetings and/or short research reports or presentations.
3. To contribute to discussion of the following issues:
  - study design (for example, content of patient interviews)
  - comment on preliminary results
  - ideas about analysis, presentation and communicating results
4. Members will have access to the main researchers (Dr. Andrea Gershon and Dr. Samir Gupta) who can offer guidance on meeting procedures and the review of materials sent prior to the meetings. Members will be able to contact these researchers before and after each meeting and to have any questions answered during the meetings.

## Person specification

<b>Factor</b>	<b>Essential attributes</b>	<b>Desirable attributes</b>
<b>Qualifications</b>	None	None
<b>Experience</b>	None	Committee experience
<b>Skills</b>	Willing to familiarize yourself with some medical and research language	To keep up to date with COVID-19 issues via media and information provided by the research team
<b>Knowledge</b>	Knowledge of perspectives from the group you represent (COVID-19 sufferer, caregiver of underrepresented group, ethno-cultural community, etc.)	To have some understanding of research
<b>Personal qualities</b>	<ul style="list-style-type: none"><li>• Good communicator</li><li>• Ability to listen to others and express own views</li><li>• Openness to other people's views</li></ul>	<ul style="list-style-type: none"><li>• Self confidence in mixed group of professionals</li><li>• Willing to give feedback to Long COVID-19 study team to help in developing their work</li></ul>

## Technical specification

<b>Infrastructure and Experience</b>	<ul style="list-style-type: none"><li>• Access to internet / email</li><li>• Access to a phone</li></ul>	Knowledge of working with virtual meeting platform
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## Activities and estimated timelines

1. Inaugural meeting with researchers	1. January 2022
2. Inform the design of data collection tool	2. January 2022
3. Progress meeting	3. Feb/March 2022
4. Review data collected and analyzed by researchers	4. June 2022
5. Progress meeting	5. September 2022
6. Advise on who to share research findings with and the ways to communicate (targeted messages to Canadians with post-COVID-19 symptoms)	6. Late 2022
7. Consult or participate in the development of clinical recommendations	7. Winter 2022/early 2023
8. Evaluate patient/caregiver and researchers' involvement in this study	8. Mid-2023

## Support and learning environment

- If you would like to be a part of this patient/caregiver advisory group, please contact:



Anne Van Dam  
Director of Knowledge Mobilization  
at the Canadian Thoracic Society  
avandam@cts-sct.ca  
or  
613-410-8634

- Anne will set up a call to review the type of supports you will require for your involvement in this study; your communication and learning environment preferences.