



Seeking Individuals with Long COVID experience and expertise for a research study Long COVID patients, caregivers, clinicians, community leaders, researchers & policymakers invited to participate

Study title: Establishing a Minimum Data Set for Long COVID Survey Questions across Canada

Study Objective: To create a consensus-based minimum data set to access Long COVID data using a Delphi process.

Why is this research being done?

The aim of our study is to determine the most important and relevant Long COVID questions to include in future surveys conducted across Canada. To do this, we are using a Delphi method. The Delphi consists of three rounds of surveys. In each round, participants indicate the question categories they feel are most important. Based on this information, categories will be kept or filtered out, so that at the end, we have a small number of categories that everyone agrees are important. Once we have these categories, a survey of 40-50 questions (a "minimum data set") will be developed and distributed across the country. This data set will allow researchers to learn about Long COVID and improve outcomes for people with Long COVID.

What does the Delphi process involve?

The Delphi process involves three rounds of online surveys taken over six months.

Who can volunteer?

To be eligible, participants must have one of the following:

- Lived experience as a Long COVID patient or as an informal caregiver for someone with Long COVID, such as a family member or friend.
- Expertise as a Long COVID clinician, researcher or policymaker.

Participants must also:

- Be 18 years or older.
- Have access to online documents and the internet.
- Be able to read and understand English.

Selected applicants will be invited to participate after completing an equity, diversity, inclusion and accessibility questionnaire.

How much of my time will the research take?

It is anticipated that this project will take 2-7 hours of your time spread out over about six months.

- Round one online survey will take about 1-3 hours. You will be able to submit responses over a 3-week period.
- Round two online survey will take about ½ hour-2 hours. You will be able to submit responses over a 3-week period.
- Round three online survey will take about ½ hour-2 hours. You will be able to submit responses over a 3-week period.

Honoraria of up to \$200 will be available to participants who volunteer their time for this project.

Where does the research take place?

The study will be conducted online via Survey Monkey and can be completed at your own time and pace.

***If you or anyone you know is interested in participating,
please contact bansari.chavda@usask.ca.***

If you need urgent medical care, call 911. If you are in distress, the following supports are available:

Adults: 1.866.585.0445 | **Indigenous Peoples:** 1.855.242.3310

This research is approved by the University of Saskatchewan Research Ethics Board.