

FAQ Document: Post COVID-19 Condition (PCC) Survey

Please reference the answers below to help address questions on the Canadian Health and COVID-19 Survey (CHCS). For additional follow-up questions, feel free to reach out to the following contacts:

- For **Provincial Rollout Questions**: Contact the Ontario Ministry of Health at SPB.PCIRB@ontario.ca.
- For **Federal PCC Planning and Response Questions**: Contact the Public Health Agency of Canada at media@hc-sc.gc.ca or Statistics Canada at statcan.mediahotline-ligneinfomedias.statcan@canada.ca.

What is Post COVID-19 Condition (PCC)?

Post COVID-19 Condition (PCC), also known as “long COVID”, is an emerging and rapidly growing health problem that is not yet well understood. There is no universally accepted definition for PCC, and numerous clinical definitions are currently in use. The World Health Organization defines PCC as symptoms experienced 12 weeks or longer after the onset of COVID-19 which cannot be explained by an alternative diagnosis.

Why am I receiving this survey?

The Public Health Agency of Canada and Statistics Canada developed a survey on the health of Canadians and the health impact of COVID-19, including questions aimed at determining the presence of Post COVID-19 Condition (PCC). Please see the Statistics Canada website for [information for survey participants](#), or for a [description of the survey](#).

The provinces have been provided with the opportunity to distribute the survey to key sub-populations in their jurisdictions. The survey aims to gain province-specific insights and inform the planning of PCC services.

What are the objectives of the survey?

The Canadian Health and COVID-19 Survey (CHCS) aims to collect information about lasting health problems and symptoms and about COVID-19 and Post COVID-19 Condition (PCC). The purpose is to gather information on the presence of and protection against these conditions, as well as health concerns, use of the health care system, and prescribed medications.

Additional objectives of the survey are to:

- Estimate the prevalence of PCC among respondents;

- Identify risk factors contributing to the development of PCC (e.g., demographic characteristics, severity of acute infection, presence of pre-existing chronic conditions, vaccination status, etc.);
- Describe the range and duration of symptoms reported; and
- Examine the impact of PCC on daily functioning.

The main objectives of the survey rollout in Ontario are to understand how Post COVID-19 Condition (PCC) affects priority populations and certain other groups of interest, and to identify how PCC services could be tailored to ensure equitable access and meet the needs of these groups.

What information will be covered in the survey?

This survey asks questions about the following health-related topics:

- COVID-19 information:
 - Symptoms (types, duration, severity)
 - Health status
 - Impacts on daily activities
- Health information:
 - Long-term symptoms
 - Long-term health conditions
 - Interactions with health care system
 - Medication use

What will the results of the survey be used for?

The survey results could be used by researchers, analysts and decision-makers across Canada to help inform the work being done around PCC. These groups include:

- Parliament and other policy makers, to track major initiatives, set priorities for prevention and research programs, and evaluate policy and program outcomes.
- Epidemiologists, biomedical and health service researchers, to understand trends in diseases and the relationship of observed risk factors to diseases.
- Public health professionals, to track preventable illnesses and evaluate the impact of prevention and intervention programs.
- Advocacy groups, to raise awareness and assist in their surveillance of health issues and health disparities.

What groups are being surveyed?

The survey aims to get input from key priority populations to ensure equitable access to services. Priority populations being those that are experiencing and/or at increased risk of poor health outcomes due to the burden of disease and/or factors for disease; the determinants of health, including the social determinants of health; and/or the intersection between them ([Health Equity Guideline, 2018](#)).

The Ministry of Health worked internally and with other ministries to identify priority sub-populations. In particular, the ministry is aiming to reach Indigenous people, racialized populations, 2SLGBTQI+ individuals, francophones, and persons with disabilities.

How long will the survey be available to complete?

The survey will be launched on July 3, 2023 and will remain active for 8 weeks. The survey will remain open until August 29, 2023.

How long does it take to complete the survey?

The survey consists of around 65 questions and is estimated to take approximately 20-30 minutes.

Is the survey confidential? Anonymous? Who will the data and information be shared with?

The survey is being rolled out in collaboration with Statistics Canada, meaning the survey falls under the [Statistics Act](#). The Act states that all information provided to Statistics Canada will be confidential and used only for statistical purposes.

All Statistics Canada employees are responsible for ensuring the security of confidential information. Only employees who need to view confidential files as part of their duties are authorized to access them. A network of physical security systems and procedures protects confidential information against unauthorized access.

Sharing Agreement & Anonymity:

Respondents will be asked for consent to share their information from the survey, including direct identifiers (which include names, addresses, telephone numbers and health care numbers), with other provincial and territorial ministries of health, Health Canada, and the Public Health Agency of Canada. Only postal codes and questionnaire responses would be shared with federal partners, and identifiers may only be shared with provincial partners upon request.

Survey data, including direct identifiers, would only be shared with your consent and with those organizations that have agreed to keep the information confidential and to use it only for statistical and research purposes.

For respondents aged 18 years and older:

To reduce the number of questions in this questionnaire, Statistics Canada will use information from your tax forms submitted to the Canada Revenue Agency. With your consent, Statistics Canada may share this information from your tax forms with Health Canada and the Public Health Agency of Canada. These organizations have agreed to keep the information confidential and to use it only for statistical and research purposes.

If I consent to participate, do I have to complete every part of the survey?

Participation in the survey is completely voluntary. A respondent may choose to withdraw from any part of the survey at any time. Also, respondents may choose not to answer specific questions if they do not feel comfortable doing so.

Why does Statistics Canada want to know my personal information (i.e., name, contact information, health care number)?

When your data reaches Statistics Canada, whether from surveys or administrative sources, some of it is used to create a demographic profile. Statistics Canada removes personal identifiers and only retains information such as age, gender, income, and geographical location. This data is merged with that of other people who share the same demographic profile (for example, groupings based on the same age, gender, income or geographical location). Even if questions related to personal information may seem irrelevant to the subject of the survey, they provide a deeper knowledge of respondents' characteristics, which allows us to create a representative sample of the Canadian population. By analyzing this large database, researchers are able to observe emerging patterns and trends and provide important information to governments, not-for-profit organizations, researchers, and the wider public.

Statistics Canada also requests personal information to avoid duplication of surveys. Respondents will be asked for consent to share their information from this survey with other provincial and territorial ministries of health, Health Canada, and the Public Health Agency of Canada.

How was this survey developed?

The Public Health Agency of Canada has worked alongside Statistics Canada to develop a national survey on the health of Canadians and the health impact of COVID-19, including questions aimed at determining the presence of Post COVID-19 Condition (PCC). As a supplement to the national survey, the Public Health Agency of Canada and Statistics Canada have allowed provinces to distribute the survey to key sub-populations in their jurisdictions to gain province-specific insights and inform planning.

Statistics Canada developed the survey content through consultations with its partners, Health Canada, Public Health Agency of Canada, and the COVID-19 Immunity Task Force. In addition, consultations with Health Canada's research ethics board and the Office of the Privacy Commissioner of Canada also took place. The survey aims to provide data that meet the

research needs and priorities of the health research community in Canada while protecting the confidentiality of information from participants.

Do Statistics Canada's online questionnaires support in-browser automatic translation?

The survey is available in both English and French. We encourage respondents to use the language button built into our questionnaires to switch between English and French, rather than using their browser's translation function. Unfortunately, when the browser translates our questionnaires, it can translate the information incorrectly.

Will the survey results be published?

In accordance with their [Policy on Official Release](#), Statistics Canada will be publishing non-confidential aggregated results from the federal survey on their public news page, [the Daily](#). Publication is anticipated in Fall 2023 (*please note that this date is subject to change*).