

CPHR



CANADIAN PH REGISTRY
Frequently Asked Questions



What is the Canadian Pulmonary Hypertension Registry (CPHR)?

The CPHR is a database of information about pulmonary hypertension (PH) patients in Canada that is used to understand how PH affects Canadians and to improve the quality of care provided to patients with PH in Canada.

The information that is collected includes patient characteristics (such as age, sex, and type of pulmonary hypertension), symptoms, laboratory findings, diagnostic tests, and treatments in a structured manner. The data collected may be used for future research studies PH, to guide and advise health policy, and to improve the way care is provided to patients in Canada.

What is the purpose of the registry?

Patient data helps researchers and medical providers better understand a disease and how to provide the best care. Data on the Canadian PH population is lacking, especially for the rarest forms of PH, PAH and CTEPH. This registry allows us to understand PH better and its impacts on patients.

Who can participate?

You may be able to participate in this registry if you've been seen by a PH specialist at one of the participating Canadian PH clinics and have been diagnosed with PH.

What do I have to do?

You do not have to do anything extra to participate in the registry. No specific treatment or research drug is given. You may be asked to answer a short questionnaire each time you have your regular PH clinic visit.

What happens if I agree to participate?

If you wish to participate in the registry, you will be presented with a consent form to review and agree to. Information collected during your regular clinic visit (symptoms, tests, and response to therapy) will be entered into an online form and stored in a secure location.

Whether you choose to participate in the registry or not, your visits to the clinic and the treatments that you are offered will not be impacted.

How is my privacy protected?

Your privacy will be respected. The information that is collected about you will not be shared with anyone with identifying information attached. The data that is collected about you is grouped with data from other patients in Canada and may be used in reports, publications, or presentations. The registry team will not release any information to anybody else that could be used to identify you.



Where is the data stored?

Registry data is stored on a secure server at the University of British Columbia and at the Vancouver Coastal Health network (only BC participants).

How do I sign up?

Contact your local PH clinic team for more information.

What is a Steering Committee?

A committee that oversees the implementation of the CPHR.

Who is part of the CPHR Steering Committee?

The Steering Committee is mainly made up of participating centers across Canada including an organization, PHA Canada (Pulmonary Hypertension Association of Canada). A member from the participating center and organization is invited to be part of the Steering Committee.

What do the CPHR Steering Committee do?

The Steering Committee is responsible for the overall direction of the registry, overseeing the progress of the project and monitoring ongoing registry operation and budget/expenses. The Steering Committee is also responsible for the oversight of collected data, data access, data transfer and storage, quality control, security, long-term management of the registry, and publication production.

