



PULMONARY HYPERTENSION
ASSOCIATION OF CANADA

L'ASSOCIATION D'HYPERTENSION
PULMONAIRE DU CANADA

The Impact of **PULMONARY HYPERTENSION** on Canadians

Thank you to everyone who completed the Canadian PH Community Survey. The stories shared will help create a better future for everyone affected by PH.

The quotes in this report have all been anonymously selected from the survey.

All photos in this report have been provided with consent.

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www.phacanada.ca

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A Message from the **BOARD OF DIRECTORS**

PHA Canada's mission is to empower the pulmonary hypertension community through support, education, advocacy, awareness, and research. To be effective, we must fully understand the impacts of a PH diagnosis on a person and their family. This understanding can only come from listening to the lived experiences of those affected by PH and then grounding our work in the answers provided.

In 2013, PHA Canada conducted a Burden of Illness (BOI) survey of the Canadian PH community. The results deepened our knowledge of the many struggles encountered along the PH journey, from significant delays to diagnosis to the many physical, social, and financial burdens experienced by people living with PH and their caregivers. The BOI survey report became a crucial tool for educating decision-makers on the complex needs faced by Canadians affected by PH and has served as a powerful advocacy tool.

Community experts designed the 2021 Canadian PH Community Survey to measure changes in the impacts of a PH diagnosis since 2013 and provide new insights into PH diagnosis, treatment, and support in Canada. They also designed it to help us learn how the COVID-19 pandemic affected the PH community, including psychological impacts, vaccination rates, and healthcare delivery changes.

The results reveal both the resiliency of the PH community and the need for continued innovation in the care and treatment of pulmonary hypertension. Diagnosis still takes too long. Treatment gaps persist. Support services are often inadequate. We hope this report inspires you to join us in raising awareness of these challenges and fighting to make them a thing of the past.



Nicole Dempsey
Chair, Board of Directors
Living with PAH since 2013



Dr. Lisa Mielniczuk
Vice-Chair, Board of Directors
Director, Ottawa Heart Institute PH Program

A Message from the **STAFF TEAM**

To work with the PH community is to witness determination, courage, and compassion daily. Determination to push back against the limitations imposed by PH. The courage to accept the unacceptable. Compassion, not only for others but for oneself. The PH community contains much wisdom, and we are deeply grateful every time they choose to share it with us.

Last year, over 400 members of Canada's PH community—representing patients, caregivers, families, health care providers, and researchers—responded to the Canadian PH Community Survey. Their responses provide us with incredible insight into the current realities of a PH diagnosis in Canada and the PH community's ongoing needs.

Thank you to everyone who filled out the survey and shared details of your PH journey with us. Our heartfelt appreciation also goes to the PH patients, caregivers, and health care professionals who sat on the survey's Advisory Committee and provided valuable oversight of the survey's development. The committee ensured that the questions asked were relevant and vital to the PH community and would allow for both evidence-based analysis and practical application.

PHA Canada is already using the information gathered to determine how best to serve the PH community, including addressing gaps in disease awareness, time to diagnosis, and the impacts of PH on quality of life. With your support, we are confident we can change the course of a PH diagnosis in Canada--shortening the time to diagnosis, improving access to worthwhile treatments, and ensuring no one faces PH alone.



Jamie Myrah
Executive Director
Vancouver, BC

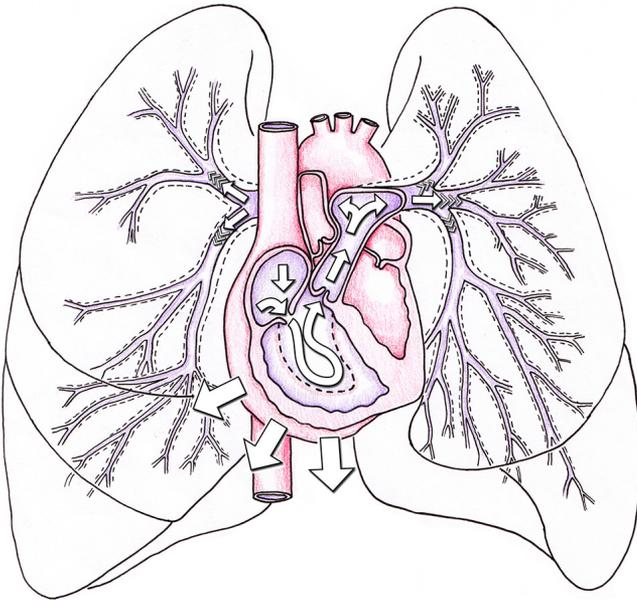


Darren Fisher
Manager of Strategic Initiatives
Toronto, ON

What is PULMONARY HYPERTENSION (PH)?

Pulmonary hypertension—or PH—is characterized by high blood pressure in the pulmonary arteries (blood vessels) that carry blood to the lungs. PH means that the blood pressure in the arteries that carry blood to the lungs is too high. This excessive pressure is usually caused by restriction or blockage in the blood vessels. PH can cause the heart to work harder and lead to heart failure.

PH is a serious disease that can be life-threatening. While the development and availability of treatment options have progressed in recent years, many people with PH in Canada continue to spend two to three years seeking an accurate diagnosis. Alarming, without treatment, the average life expectancy of a person with PH is less than three years.



Learn more at phacanada.ca/videos

Who Does PH AFFECT?

It is estimated that approximately 5,000 Canadians have been diagnosed with pulmonary hypertension, but as many as 10,000 may be affected by the condition.

PH can strike anyone regardless of age, sex, or social/ethnic background.

Physical symptoms can include:

- ▶ Persistent or unexplained shortness of breath (especially upon exertion)
- ▶ Fatigue/loss of energy
- ▶ Swollen ankles and legs (also called edema)
- ▶ Chest pain
- ▶ Bluish lips, hands, and feet
- ▶ Dizziness upon activity, including walking, climbing stairs
- ▶ Fainting (also called syncope)



About the SURVEY

The Canadian PH Community Survey was conducted from May 5 to July 5, 2021 (for patients and caregivers) and from June 26 to September 30, 2021 (for PH health care professionals). The goal of the survey was to measure the physical, social, financial, emotional, and psychological impacts faced by the Canadian PH community. Additionally, the survey captured data relevant to evaluating PHA Canada’s strategic goals and priorities to ensure we are succeeding in empowering the Canadian PH community and providing the resources necessary to improve the lives of all Canadians affected by PH.

The survey was designed under the guidance of an Advisory Committee consisting of patients, caregivers, and healthcare professionals. To ensure accessibility, the survey was available in both French and English, promoted widely through multiple media channels, and was available both online and by phone. The result was a robust response from 305 patients, 77 caregivers, and 24 healthcare professionals, surpassing the 2013 BIO survey response of 118 patients and 61 caregivers (note: health care professionals were not surveyed in 2013).

Who responded



305
Patients



77
Caregivers



24
Health Care
Professionals

Total = 406 responses

PH and COVID-19

The Canadian PH Community Survey was conducted just over a year into the COVID-19 pandemic. At the time, most patients (98%) and caregivers (97%) had **not contracted COVID-19**, and most patients (96%) and caregivers (93%) had received at least **one dose of a COVID-19 vaccine**.

The COVID-19 global pandemic presented significant challenges for everyone and unique challenges for those living with chronic illnesses, such as pulmonary hypertension. People with PH may be vulnerable to more severe disease caused by a COVID-19 infection, leading to understandable fear, anxiety, and isolation within the PH community.

Patients and caregivers reported that:

- ▶ 42% felt **fearful or frightened**
- ▶ 42% **avoided leaving home**, including for essential travel
- ▶ 40% had **no desire to socialize**
- ▶ 37% felt **isolated**
- ▶ 35% felt **angry or frustrated**

The pandemic also required patients to adjust how they received their medical care. For many, seeing a medical professional in person was no longer possible. The majority were required to rely on virtual health care, including telephone and video calls with their medical teams.

- ▶ 60% of patients surveyed **accessed virtual health care** at least once in the past year
- ▶ 69% of patients were **satisfied with the virtual health care** provided by their PH team
- ▶ 43% of patients would like to **continue using virtual health care** with their PH team



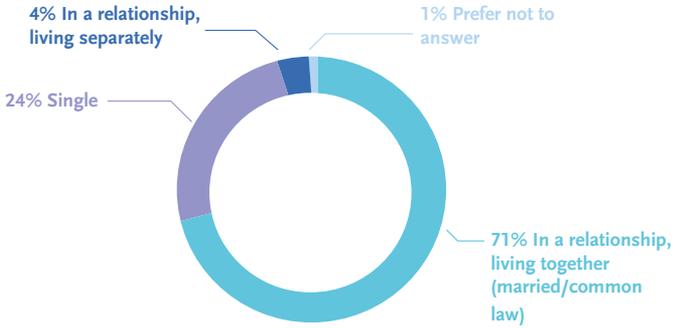
Except for the necessary tests relating to diagnosis, I have not had in-contact visits. Phone calls are great as I don't have to leave the house; however, I do find that it's more difficult to communicate, especially as a new patient who has only met my doctor once during a diagnosis procedure.

Who Completed the SURVEY?

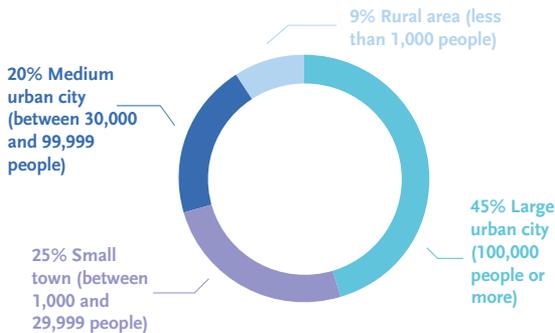
Age/Gender

	Patients	Caregivers
Mean age	58 years old	53 years old
Male	11%	41%
Female	88%	59%
Non-binary/ third gender	0.3%	–

Relationship Status

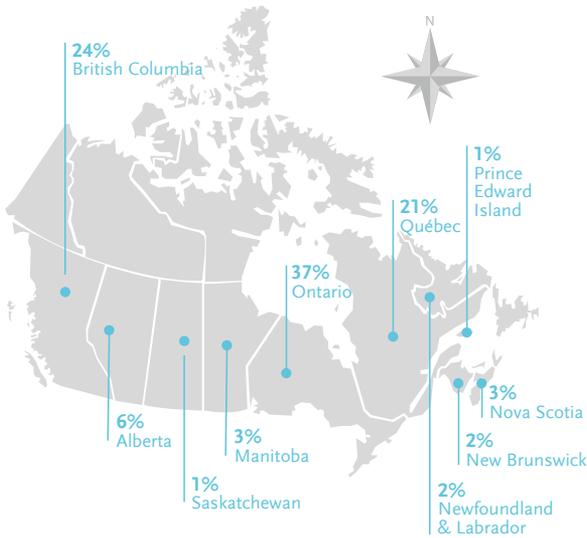


Type of location



Who Completed the SURVEY?

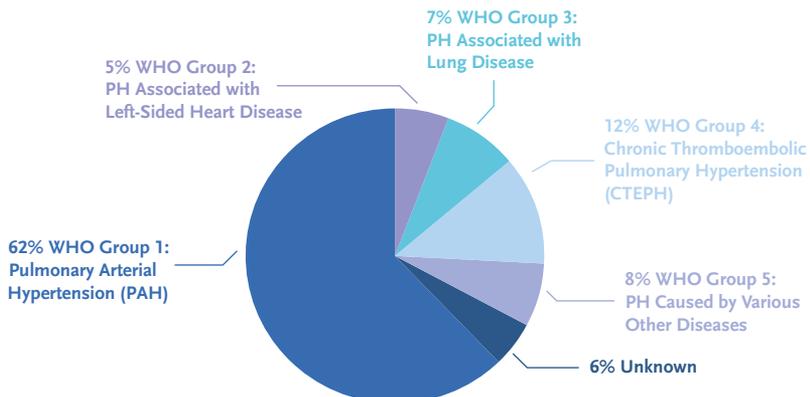
Location



Language



Type of PH reported by patients



Understanding DIAGNOSIS

Pulmonary hypertension can be difficult to diagnose because the symptoms of PH are quite similar to those of many other lung and cardiac diseases. A series of tests that indicate how well a person's heart and lungs are working can establish a diagnosis of PH and assess the severity of the disease.

These tests may include:

- ▶ **Echocardiogram** (ultrasound of the heart)
- ▶ **Right heart catheterization** (direct measurement of pressure in the pulmonary arteries and a test of how well the heart is pumping blood to the body)
- ▶ **Pulmonary function tests**
- ▶ **Chest x-ray, EKG, etc.**
- ▶ **Blood tests** (for conditions associated with PH)

46

Average age of the patients surveyed at diagnosis

7

Average number of years the patients surveyed had lived with PH



Delays to **DIAGNOSIS**

The survey reveals that although patients appear to be more proactive in seeking medical treatment for their symptoms, many are still experiencing a **delay in diagnosis of more than two years**. This remains similar to the results of the 2013 BOI survey despite increased education for primary care providers.

50%

of all patients surveyed reported the time from the first symptom to **diagnosis was more than two years**

69%

of patients reported **visiting their doctor/emergency department within at least a year of first noticing symptoms**

69%

of patients report **receiving a confirmed PH diagnosis within a year** of their initial visit to a doctor

70%

of patients surveyed reported that their **primary care provider/family doctor did not initially recognize their symptoms** as possibly indicating PH (up from 51% in the 2013 BOI survey)

44%

of patients report having **up to four appointments related to their PH symptoms before receiving their first referral to a PH specialist**

“

I had signs of PH in 2003 but myself and the medical community did not recognize them. I barely passed an oxygen test. Plus passing out and falling down. It was classed as falling down disease.

Gaps in TREATMENT

Many medications are approved in Canada to treat PH, helping to alleviate symptoms and improve functioning and quality of life. Medical treatment can also slow the progression of PH and improve heart and lung function; however, they do not provide a cure for PH. CTEPH is the only type of pulmonary hypertension that may be curable through a specialized surgery called pulmonary thromboendarterectomy (PEA).

- ▶ Almost half of all patients use **oxygen** at least sometimes, with 21% using oxygen full-time
 - ▶ More than half of CTEPH patients surveyed had undergone **PEA/PTE surgery** (55%)
 - ▶ Almost two in three PAH patients are on **combination therapy**, either dual (33%) or triple (27%)
-

62%

of patients and caregivers believe that there need to be **more treatment options** for PH

57%

The majority of patients and caregivers agreed that the most important thing they were **looking for in a PH treatment was an overall improvement in quality of life**

20%

of patients and caregivers surveyed report that **side effects have gotten in the way of achieving optimal treatment**

44%

Many patients (36%) and caregivers (44%) report that **PH has a bigger negative impact on their lives now** than it did when they or their loved ones were first diagnosed

82%

of patients surveyed felt **involved at each stage of making treatment decisions**

Physical BURDENS

Like in 2013, the 2021 survey demonstrates that PH and its treatments take a significant physical toll on patients, including limitations to daily activities, reduced independence, and changes to intimate relationships.

- ▶ Side-effects that most negatively impact patients' quality of life are **headaches** (28%), **gastroesophageal reflux** (27%), and **diarrhea** (21%)
- ▶ Almost half (44%) of patients report that PH has negatively impacted their **level of interest in or ability to have sex**
- ▶ Almost one in four patients surveyed admit that PH negatively affects their **self-esteem and body image**



“

Because of the symptoms, changes in body/weight/abilities etc., I have stopped any ideas for any possible future relationships as I feel I am not worthy of that, nor do I want to put anyone in a position to be my caregiver...

Social IMPACTS

In addition to changes to their relationships, many patients and caregivers surveyed report experiencing social isolation due to a lack of understanding and awareness of PH among friends, colleagues, and the public.

- ▶ Nearly one in three patients surveyed say their **role in personal relationships** with their partner/spouse (26%), friends (35%), and within their family (33%) has changed due to their PH
- ▶ Almost one in four caregivers feel that their **role within their family** has changed in a negative way
- ▶ More than half (52%) of patients and caregivers surveyed feel **isolated and excluded from society because PH is not a 'visible' disease** (down approximately 15% from what was reported in the 2013 BOI survey)
- ▶ Nearly two in three of all patients and caregivers surveyed **wished that the public knew more about the disease itself**



“

This has been the hardest thing I have had to learn to live with. It has taken my life from me as I knew it. It changed how I parent. It has changed my ability to be a wife. It has changed my want to be social because of how hard it is.

Financial IMPACTS

A PH diagnosis can impact the financial health of both patients and caregivers. Due to the physical limitations of the disease, patients often find it very difficult to maintain their employment, with nearly half (45%) of patients surveyed reporting that PH has **negatively impacted their employment status**.

There is a similar impact on caregivers, with just over 40% of caregivers reporting a **negative effect on their employment status**. The loss of employment not only affects the ability to pay for household essentials, but it can also impact access to optimal treatment if patients lack employer-provided drug insurance.

- ▶ Almost 50% of caregivers surveyed indicated that the diagnosis of their loved one has forced them to take **one or more temporary leaves from work or school**
- ▶ Almost 40% of patients and caregivers surveyed report that their **financial situation due to PH negatively impacts their mental and emotional wellbeing**
- ▶ More than a third (35%) of patients surveyed report being more **dependent on income assistance from personal and government sources** since being diagnosed with PH
- ▶ 14% of patients and caregivers surveyed indicate that they are **paying directly for at least partial private drug coverage**

“

I have only recently been diagnosed; so far, I am struggling with the financial implications as there are so many unknowns.



Support and Education **NEEDS**

Pulmonary hypertension is a life-changing condition that can leave both patients and caregivers feeling powerless and alone. Fortunately, most patients surveyed report feeling **knowledgeable about PH (90%), their treatment options (80%), and how to actively manage their physical and mental health (79%)**. Yet, many still report a lack of connection to their peers in the PH community and other valuable community resources.

- ▶ Patients list their caregivers (92%), PH physician (88%), and PH nurse (85%) as their **top sources of emotional support**
- ▶ A third of patients (34%) and half of caregivers (49%) surveyed report **needing access to counseling and emotional support** because of a PH diagnosis
- ▶ 30% of patients surveyed are **interested in accessing pulmonary/cardiac rehabilitation** but do not have access to it
- ▶ 46% of patients surveyed indicate that they are **interested in participating in clinical trials** but do not have access to them
- ▶ **Future PH treatment options** was the top information need identified by both patients and caregivers



“

It's easy to see my specialist but not nearly as effective as going. I am going to see my PH specialist as soon as it's safe to travel.

How can you **HELP?**

No two journeys with PH are alike, yet all people living with pulmonary hypertension deserve equitable and timely access to the best care possible. Decision-makers, health care providers, and the public must work together to enhance awareness of PH, diagnose patients sooner, and ensure universal access to optimal treatment and support throughout Canada.

We need your help. Contact us by email, phone, or mail (below) or visit us online to learn more about PH and what you can do to improve the lives of all Canadians living with pulmonary hypertension.

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