Canadian Pulmonary Hypertension Priority Setting Partnership (PSP)

Do you have questions about pulmonary hypertension? If so, we want to hear from you.

What is pulmonary hypertension?

Pulmonary hypertension is caused by high blood pressure in the lungs. It can happen at any age. Pulmonary hypertension causes difficulty for the heart to pump blood through the lungs, which can lead to symptoms of breathlessness, heart palpitations, ankle swelling and fatigue.

Why is this survey important?

Despite significant treatment advances, pulmonary hypertension remains a progressive disease. Pulmonary hypertension affects all age groups and leads to reduced quality of life of patients and families. There are considerable economic and social consequences of living with pulmonary hypertension including limitations with everyday activities and the inability to work. In some cases, caregivers have to alter their employment to care for someone with pulmonary hypertension.

The purpose of this research study is to identify your priorities and questions that you want answered regarding pulmonary hypertension. We want to find out what research is needed for people with pulmonary hypertension. This survey is an opportunity for you to tell us what is most important to you about pulmonary hypertension so that we can share your priorities with research funders. If you are a pulmonary hypertension patient or look after someone with pulmonary hypertension, we would like to hear from you. This is the time for you to be heard and influence important research that will have an impact on your life.

Who should take part in this survey?

- Patients with pulmonary hypertension
- Caregivers, family and friends of patients with pulmonary hypertension
- Healthcare providers (including nurses, physicians, pharmacists, social workers, patient societies and others) who care for patients with pulmonary hypertension

Do I have to take part in the survey?

Your participation in this survey is voluntary and you have the right to refuse participation.

What is involved if I take part in this survey?

If you volunteer to participate in this study, you will be asked to complete a brief survey. The survey includes three sections. The first section asks about your own experience with pulmonary hypertension. The second section asks what questions you would like answered about pulmonary hypertension. The last section of the survey asks you to provide some information about yourself. The survey will take about 5 -10 minutes to complete. You do not have to answer any questions that you do not want to answer.

You can access the survey in a number of different ways:

- online: www.phacanada.ca/JLAsurvey.html or www.htapquebec.ca/JLAsurvey.html
- clicking on the links sent via email invitations from PHA Canada or HTAPQ
- directly at www.phpsp.ca

At the end of the survey, you will be asked if you would like to participate in the second phase of the study by helping to decide which of the topics identified by the survey are the most important. If you are interested, you will be asked to provide your name and contact information. We will only contact you if you provide this information. Otherwise, your survey responses and participation will be kept confidential and we will not contact you again.

Although participating in this survey is voluntary, once you hit “submit”, you will not be able to withdraw or go back to edit your responses.

Are there any potential benefits if I participate?

There will be no direct benefit to you from participating in this study. However, this study may help the researchers focus on the things that matter most to pulmonary hypertension patients and clinicians.

Will my answers be kept confidential?

All answers are completely confidential and anonymous. Any personal information collected will be kept confidential and when we release the results of this survey, we will never identify any individual who took part in this survey. Regardless of your geographical location, your survey responses will be sent directly to the lead researchers at the University of Calgary. **If you provide your contact information to participate in the second phase of the study, the Calgary research will have access to this information.** Data will be kept confidential by the study team and securely stored at the University of Calgary and only the study team will have access to it. The study team will not be comparing your contact information to the responses you have provided.

Who is supporting this survey?

This study is being funded by the Canadian Institutes of Health Research (CIHR) and the Libin Cardiovascular Institute of Alberta. The study follows the rigorous scientific methods of the James Lind Alliance (http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/), a non-profit initiative based in England.

What will happen to the results?

Your question(s) will be gathered together and examined with questions we receive from all survey participants. We will check to see if these have already been answered by previous research. If previous research has not adequately answered all questions, a top 10 list will be made during a workshop consisting of a working group of pulmonary hypertension patients, caregivers and healthcare providers.

The list will be published and will be used to influence future research decisions. The final results will be made public on the Pulmonary Hypertension Association of Canada and Hypertension Artérielle Pulmonaire Quebec websites. We will work to promote the results with other researchers and organizations that fund research to inform their research funding program.

We will share the results of this project as widely as possible with groups that fund and carry out research. We will also inform the charities and patient associations that work with those affected by pulmonary hypertension.

Who can I contact for more information?

If you would like more information about the survey or have any questions or concerns about the research or your participation in this study, please go to **www.phpsp.ca** or contact:

Dr. Jason Weatherald (Principal Investigator) - Pulmonary Hypertension Priority Setting Partnership Lead
Email: jcweathe@ucalgary.ca
Telephone: 403-943-4779

OR

Hina Iqbal - Pulmonary Hypertension Priority Setting Partnership Coordinator
Email: hina.iqbal@ucalgary.ca
Telephone: 403-210-7447

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

By answering the questions that follow, you are consenting to participate in this project.

Thank you for your participation and helping to influence important research that will have an impact on those living with pulmonary hypertension.

Every question in every section is optional.
Answer only the questions you feel comfortable answering.

STEP 1: Your questions about pulmonary hypertension

In step 1, we are asking for your questions and challenges related to pulmonary hypertension. When you answer, please:

•Think about your own personal and/or professional experience with pulmonary hypertension. Your experience is what makes you the expert.

•Provide the question(s) about pulmonary hypertension that are important to you and went unanswered for you. To do this, it might be helpful to ask yourself "if it was up to me, where would I spend money on pulmonary hypertension research?"

•Remember research can cover a wide variety of topics. Researchers can study almost any aspects of pulmonary hypertension including physical, mental, emotional and societal factors.

•Don't worry about which box to write your question(s) in. Some of the questions might seem similar or overlapping. If so, please write your responses in any box you feel is appropriate.

•Write any question you feel is important regardless of if you think that someone else might ask them or that they may have already been answered. We will check if there is research that has answered the questions.

1. What question(s) about the **diagnosis** of pulmonary hypertension would you like to see answered by research?

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2. What question(s) about the **causes** of pulmonary hypertension would you like to see answered by research?

3. What question(s) about the **risk factors** of pulmonary hypertension (e.g., genetics, toxic/medication etc.) would you like to see answered by research?

4. What question(s) about the **aggravating factors** of pulmonary hypertension (e.g., pregnancy, altitude etc.) would you like to see answered by research?

5. What question(s) about the **treatment** of pulmonary hypertension would you like to see answered by research?

6. What question(s) about the **management** of pulmonary hypertension (e.g., symptoms, side effects, navigating health services etc.) would you like to see answered by research?

7. What question(s) about **living well** with pulmonary hypertension (e.g., life at work or school, mental health, relationships, finances, leisure etc.) would you like to see answered by research?

8. What question(s) about **managing the co-existing conditions** with pulmonary hypertension (e.g., heart disease, arthritis, depression, anxiety etc.) would you like to see answered by research?

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9. What **other** question(s) about pulmonary hypertension would you like to see answered by research that you feel are important but do not fall into the areas above?

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STEP 2: Your information

In step 2, we ask for some information about you so that we can understand who has responded to our questionnaire and make sure we hear from all groups. This information is also important for us to explore whether questions are consistently different between genders, regions or other groups. All personal information will remain anonymous and strictly confidential.

Please complete the following section to the best of your abilities.

10. In relation to pulmonary hypertension, which of the following role best describes you? Check all that apply.
    - A patient with pulmonary hypertension
    - Caregiver or former caregiver of someone with pulmonary hypertension
    - Friend or family member of someone with pulmonary hypertension
    - Healthcare provider for patient with pulmonary hypertension (e.g. physician, nurse, pharmacist)
    - Administrator or professional in a health care system organization
    - Part of an organization or charity that represents people with pulmonary hypertension
    - Other, please specify: _____________
    - Prefer not to say

11. To which gender do you most identify?
    - Male
    - Female

- Other, please specify: ____________
- Prefer not to say

12. What is your age?
    - Under 18 years
    - 18-34 years
    - 35-49 years
    - 50-64 years
    - 65-79 years
    - 80 years and older
    - Prefer not to say

13. What is your ethnicity?
    - North American Indigenous (First Nations)
    - African/Black Heritage
    - Chinese
    - Filipino
    - Japanese
    - Korean
    - Latin American
    - Middle Eastern (e.g., Arab, Iranian)
    - South Asian (e.g., Indian, Pakistani)
    - South East Asian (e.g., Vietnamese, Malaysian)
    - Native Hawaiian or Other Pacific Islander
    - White (Caucasian)
    - Mixed
    - Other, please specify: ____________
    - Prefer not to say

14. What is your province of primary residence?
    - British Columbia
    - Alberta
    - Saskatchewan
    - Yukon
    - Northwest Territories
    - Nunavut
    - Manitoba
    - Ontario
    - Quebec
    - New Brunswick
    - Nova Scotia
    - Prince Edward Island
    - Newfoundland & Labrador
    - Other, please specify: ____________
    - Prefer not to say

15. Which category best describes the community in which you live or practice?

- Very large population center (more than 500,000)
- Large population center (100,000 – 500,000)
- Medium population center (30,000 – 99,999)
- Small population center (1,000 – 29,999 people)
- Rural area (less than 1000)
- Do not know

16. What is the highest certificate, diploma or degree that you have completed?
    - Less than high school diploma or its equivalent
    - High school diploma or a high school equivalency certificate
    - Post-secondary certificate or diploma (including college, CEGEP or trades)
    - University degree
    - Prefer not to say

Complete questions 17, 18 and 19 if you are a person with pulmonary hypertension:

17. How many years ago were you diagnosed with pulmonary hypertension? ____________

18. Are you currently receiving treatment for pulmonary hypertension?
    - Yes
    - No

19. To the best of your knowledge, what type of pulmonary hypertension do you have?
    - Pulmonary arterial hypertension (PAH)
    - Pulmonary hypertension secondary to left heart disease
    - Pulmonary hypertension secondary to lung disease
    - Chronic thromboembolic pulmonary hypertension (CTEPH)
    - Mixed causes of pulmonary hypertension
    - Other, please specify: ____________
    - I don’t know.

Complete question 20 if you are a partner, relative, or friend of a person with pulmonary hypertension:

20. How many years ago was your family member or friend diagnosed with pulmonary hypertension? ____________

Complete questions 21 and 22 if you are a healthcare provider to a patient with pulmonary hypertension:

21. What is your healthcare profession?
    - Physician
    - Nurse or nurse practitioner
    - Pharmacist
    - Rehab Specialist (PT/OT/SLP)
    - Respiratory Therapist
    - Home Care Provider
    - Social Worker

    - Psychologist/Psychotherapist
    - Other, please specify: ____________

22. How many years have you been caring for patients with pulmonary hypertension? ____________

STEP 3: Your contact information

In step 3, we will ask if you would like to be contacted in the coming months to go through the list of research topics and tell us which ones you think are most important. This next phase of the study involves putting the research topics identified from this questionnaire into the order of importance at an in-person workshop.

If you are interested in participating in this next phase of the study, you can provide your name and contact information.

Please answer a few questions regarding the follow-up to this survey on the following page. Your answers will help to influence future research decisions in pulmonary hypertension.

Are you interested in taking part in the next phase?
- Yes
- No

Would you like to be informed on the progress of the project and the results?
- Yes
- No

If you answered "yes" to either of these questions, then please provide your name and contact information below. Upon receipt, your name and contact information will be transferred to the study master list and deleted from this survey in order to maintain your confidentiality. If you do not wish to participate any further, just leave this section blank.

Your Name: ____

Email: ____

Phone: ____

How would you prefer to be contacted?

- Email
- Mail
- Phone

If you would like to be contacted via mail, please complete the section below:

Street Address: ____

City/Town: _________________________Province: ________________________________

Postal Code: ____

You may also provide your contact information by contacting the study office:

Hina Iqbal - Pulmonary Hypertension Priority Setting Partnership Coordinator
69 HMRB - University of Calgary
3310 Hospital Drive Northwest, Calgary, AB T2N 4N1
Email: hina.iqbal@ucalgary.ca
Telephone: 403-210-7447

Please note that providing your contact information does not mean you have to participate in the next phase; ongoing participation is voluntary and you can refuse to take part when we contact you.

Thank you for your time and collaboration.