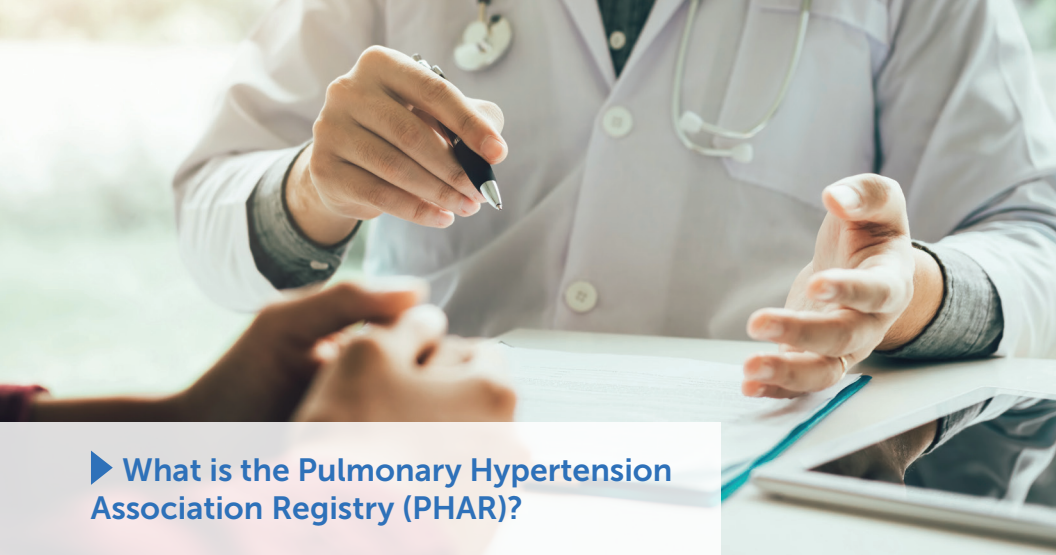




Pulmonary Hypertension Association  
Empowered by hope



## ► What is the Pulmonary Hypertension Association Registry (PHAR)?

One of the opportunities for a PHA-accredited PH Care Center (PHCC) is to invite new pulmonary arterial hypertension (PAH) and chronic thromboembolic pulmonary hypertension (CTEPH) patients to participate in the Pulmonary Hypertension Association Registry (PHAR). A patient registry is an organized system that collects data to evaluate certain outcomes for a population of people with a medical condition (like pulmonary hypertension, or PH) and is a good way to learn more about a rare disease. Because there are so few PAH and CTEPH patients, looking at data for patients from just one PHCC will not provide enough information for researchers to make meaningful discoveries about the disease. In order to determine how best to care for patients, doctors and scientists need to compile data from as many patients as possible to share with other health care

professionals and create best practices and standards of care.

That's why PHA is asking people with PH to consider joining the registry. PHAR is a computerized database that securely stores information from people around the United States with PAH or CTEPH.

People with PAH, CTEPH and pediatric PH due to developmental lung disease who are starting evaluation and/or treatment at a PHCC are invited to contribute information to the registry; the type of information collected is determined by doctors, scientists and other patients. Over time, PHAR will help researchers evaluate trends and practice patterns to determine which treatments work best. As an added bonus, doctors and nurses will be learning what treatments other clinicians are using that could potentially benefit their patients.

## ► What information is collected?

In order to be effective and reach its goals, the registry must collect a range of information about you and your PH.

Of course, in order to understand your PH, we'll need data such as:

- **Your diagnosis details**

For example: When were you diagnosed? What tests were used in making your diagnosis? What were the results of your first right heart catheterization?

- **Your clinical status**

For example: How much trouble do you have doing activity? Have you been in the hospital or in the emergency room? What are your current medications?

- **Your follow-up information**

For example: Has there been a change in your disease? A change in medications?

PHAR also needs to collect some personal identifying information that will help us identify you in the registry and keep track of you if you move to a different PHCC or change your name. We understand how sensitive this information is; read on to learn what safeguards PHAR has established to protect your personal information. This identifiable information will include your:

- Birth name and current name
- Date of birth
- Birth city, state and country
- Current street address, city, state and zip code
- Phone number
- Social Security number (optional)

## ► Where will my information be stored?

The data is stored at the Collaborative Health Studies Coordinating Center (CHSCC) at the University of Washington. CHSCC has more than 25 years of experience running medical

studies and clinical trials. They have collected research data for many studies. CHSCC will not release your personal information to anyone else.

## ► How will you protect my personal information? What if I change my mind?

To protect your identity and information, data is collected at your PHCC on a computer that

is used just for PHAR. The data will be secretly coded (encrypted) before it is sent to CHSCC. We

use similar technology in our daily lives to transfer money in our bank accounts and pay bills or buy items online. Once it arrives, the coded data is converted back to the original information and stored on a computer designated just for PHAR.

If you sign the consent form giving permission to collect and store your information, you can change your mind at any time. The PHCC would just have you sign a form notifying PHA to remove your data from the registry.

## ► Who will be able to see the data?

The only people able to see all of the data in the registry are those who are directly managing the research project: the project managers at the CHSCC and the study coordinator at the PHCC.

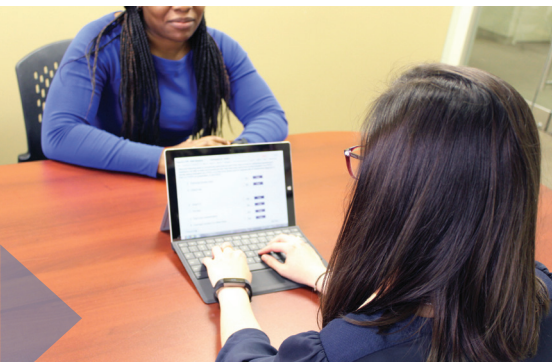
After that, unless approved by a committee reviewing a scientific proposal, no one

else will have access to data. Other investigators who have data analyses approved would only have access to limited datasets that remove ALL of your personally identifiable information. **Under no circumstances would any identifying data be released.**

## ► How much time does it take to participate in PHAR?

The first time information is collected it may take up to 20-30 minutes. There are several questions that will only be asked when you first enroll since the answers will not change, such as your birth date and where you were born. We anticipate later updates to take only about

10-15 minutes. These updates will happen about every six months. You might be asked similar questions on the update questionnaires to see if your answers to these questions have changed since your last registry visit.



The first time information is collected it may take up to 20 - 30 minutes.

Visit [PHAssociation.org/PHAR](https://PHAssociation.org/PHAR) to see why your data matters.

## ► What are you asking me to do?

We are asking you to consider participating in PHAR. A growing number of accredited PHCCs across the U.S. have been enrolling patients with PAH and CTEPH in PHAR since 2015. Enrolling as many patients as possible in the shortest time frame will allow a timelier evaluation of the data. More than 1,200 people with PH have joined PHAR to fight back against PH.

If you decide to enroll and sign the informed consent form,

you will be asked to fill out a survey on a tablet computer. Your PHCC team will also fill out a form about you. When you are seen in clinic, you will be asked to complete a brief follow-up survey about your symptoms and overall health status approximately twice each year. Your health care professional (or assistant) will also complete follow-up surveys.

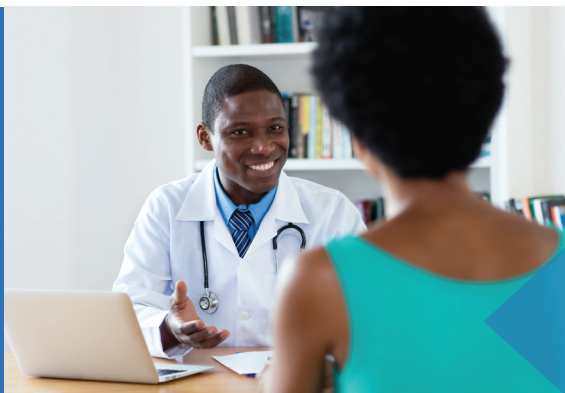
## ► How could the PHA Registry benefit me personally?

Over time, PHAR may improve the quality of care for PH patients. PHAR will allow researchers to study disease patterns in the hopes of finding a cure and could lay the foundation for funding future studies of PH

and PH treatments. It will also give you the opportunity to help other PH patients by allowing health care professionals to learn best care practices from each other.

Over time, PHAR may improve the quality of care for PH patients.

For more information, visit: [PHAssociation.org/PHAR](https://PHAssociation.org/PHAR).



## ► What is the Pulmonary Hypertension Association?

Founded in 1991 by patients, for patients, PHA is the oldest and largest nonprofit patient association in the world dedicated to serving the PH community. To achieve its mission, PHA engages individuals with PH and their families, caregivers, health care providers and researchers worldwide.

PHA also wants PH patients to receive the best quality care. To do that, PHA started a Pulmonary Hypertension Care Centers (PHCC) accreditation program. The accreditation program helps patients select care centers that meet specific criteria for providing PH patients expert care.

The mission of the Pulmonary Hypertension Association is to **extend and improve the lives of those affected by pulmonary hypertension.**



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