



**Pulmonary Hypertension
Global Patient Survey**

PHGPS Data and Insights Guide

This summary outlines the potential insights that can be gathered from the global patient survey on pulmonary hypertension (PH). The survey is designed to capture the lived experiences of individuals with PH from multiple perspectives. To achieve this, it is structured with three parallel 'arms', or versions, of the questionnaire:

Adult patient: Completed by an adult with a PH diagnosis.

Proxy for an adult: Completed by a parent, guardian, spouse, partner, or caregiver on behalf of an adult patient.

Proxy for a child: Completed by a parent or guardian on behalf of a child with PH (1 to 16 years) with PH. (137 responses)

The survey reached nearly 4,000 patients and caregivers across 90 countries.

This guide summarises the set of questions available across all three arms. However, it is essential to note that the exact wording and relevance of certain questions may vary slightly depending on the specific arm being used. As a starting point for analysis, it is important to first segment the data by the 'respondent role' to ensure the insights are interpreted from the correct perspective.

Please note...When a variable has fewer than five responses, the data is considered potentially identifiable and cannot be shared to ensure patient confidentiality.

Part 1: Demographics and Patient Profile

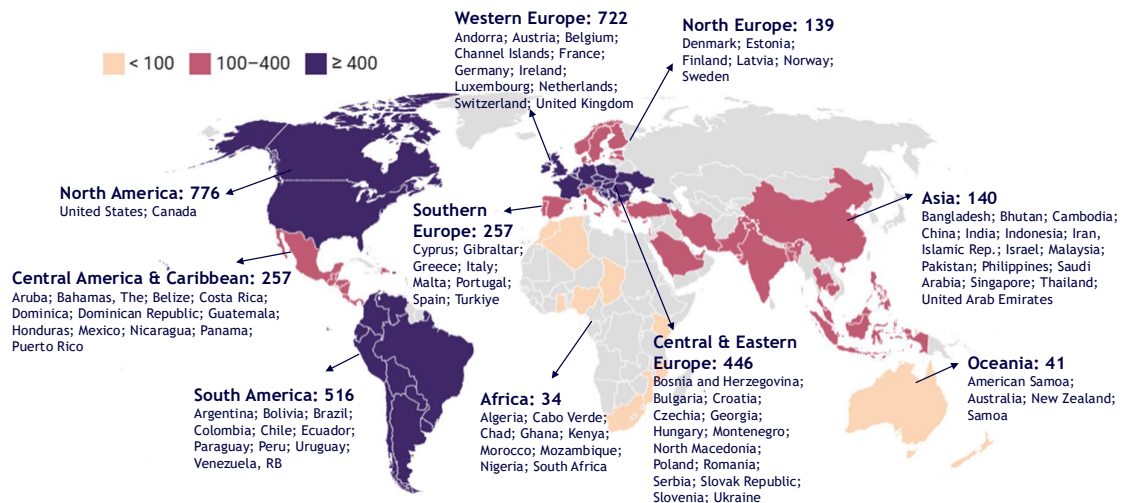
This section captures a profile of the survey respondent and their connection to pulmonary hypertension.

Respondent role: This is a categorical variable. The data will show who is filling out the survey (e.g. patient, caregiver, parent). This is crucial for segmenting the data and understanding the perspective from which the answers are provided.

- **Insights:** You can analyse how a caregiver's experience with the healthcare system differs from a patient.

Country of residence: This is a categorical variable with a long list of countries.

Number of respondents..



- **Insights:** Allows for geographical analysis. You can compare patient experiences, treatment options, and access to care across different countries and healthcare systems.

Year of birth: A numerical variable.

- **Insights:** You can calculate the age of respondents and analyse how age correlates with diagnosis, treatment, and quality of life.

Sex assigned at birth: A categorical variable.

- **Insights:** This data can be used to identify any potential differences in diagnosis or treatment experiences based on sex.

Pre-diagnosis awareness: A simple (Yes/No) categorical variable.

- **Insights:** This provides a measure of public awareness of pulmonary hypertension and can highlight opportunities for educational campaigns.

Part 2: Diagnosis and Disease Classification

This part provides core clinical data about the patient's condition.

PH diagnosis group: A categorical variable with mutually exclusive choices.

- **Insights:** This is a key variable for segmenting the data by PH type (e.g. PAH, PH with lung disease). Most analyses will need to be run separately for these groups.

Specific PAH diagnosis: A categorical variable, which is a sub-variable of **PH diagnosis group**. This question is only relevant for those who selected "Group 1 - pulmonary arterial hypertension (PAH)" in **PH diagnosis group**.

- **Insights:** Provides more granular data on the specific type of PAH, which is important for understanding the patient journey.

Genetic testing: These are a series of categorical and text variables.

- **Insights:** This data can reveal the prevalence of genetic testing, the reasons for not getting tested (e.g. cost, lack of access), and the patient's experience with the process (e.g. long wait times for results).

Part 3: Treatment and Care

This section explores the different types of treatments, surgeries, and related experiences.

Surgery and procedures: A set of categorical, numerical (for number of sessions), and scale variables.

- **Insights:** You can determine the percentage of patients who undergo specific procedures like PEA or BPA. The scale questions provide qualitative data on the perceived effectiveness of these treatments from the patient's perspective.

Time to diagnosis: An ordinal categorical variable.

- **Insights:** This is a critical metric for understanding diagnostic delays. The data can highlight the average time it takes for a patient to be diagnosed, which can be a target for future advocacy or healthcare improvement initiatives.

PH medications: A multi-select categorical variable.

- **Insights:** This data provides a comprehensive view of the most common medications used by patients, as well as the use of combination therapies.

Side effects: A combination of (Yes/No), multi-select categorical, and text variables.

- **Insights:** This data can identify the most frequently reported side effects and whether patients feel their concerns are being addressed by their healthcare provider.

Other treatments/transplant: A set of (yes/no) and categorical variables.

- **Insights:** This can provide information on the use of oxygen therapy and the number of patients who have undergone or are awaiting a transplant.

Part 4: Quality of life and patient empowerment

This section focuses on the patient's daily life, use of technology, and overall experience.

Disabled status: A yes/no and multi-select categorical variable.

- **Insights:** Shows the prevalence of official disability status among patients and the types of benefits they receive, which can vary significantly by country.

Clinical trials: A combination of (yes/no), ordinal (scale), and text variables.

- **Insights:** This data can reveal patient attitudes toward clinical trials, their experiences, and what motivates or deters them from participation.

Self-monitoring and technology: A variety of categorical variables.

- **Insights:** This section is vital for understanding patient engagement with their own care. It reveals how many people monitor their condition, what tools they use, and their comfort level with using technology like smartphone apps for health management.

Activity level: This is a Likert scale (likely 1-5, though not specified).

- **Insights:** Provides a subjective measure of how the patient's condition impacts their physical activity.

Patient Reported Outcomes (PROs): A mix of yes/no, multi-select categorical, and text variables.

- **Insights:** This is a dedicated section for understanding the patient's experience with PROs. You can analyse which questionnaires are used, how often they are completed, and whether the data is used to inform treatment decisions.

Impact on daily life: A set of Likert scales.

- **Insights:** These questions provide a direct measure of the impact of PH on specific aspects of daily living, from routine tasks to social and sexual relationships.

Discussion of negative impact: A multi-select categorical variable.

- **Insights:** This can show the support networks patients rely on when struggling with the emotional or social aspects of their disease.

Part 5: Social, emotional, and practical impact

This section explores the broader effects of pulmonary hypertension on a patient's life, including work, mental health, and social support.

Pregnancy concerns: This is a Likert scale variable.

- **Insights:** This provides insight into the psychological burden of PH, specifically for patients who may be of child-bearing age. It can help identify the level of concern and the need for dedicated counselling or support services.

Additional comments: A text/qualitative variable.

- **Insights:** This is an open-ended question that allows for rich, nuanced data. Patients can express concerns or experiences not covered by the structured questions. This is invaluable for identifying new areas of research or patient need.

Employer/school knowledge and support: A categorical variable.

- **Insights:** The data can show the level of disclosure and support in professional and academic settings. This helps identify potential discrimination or a lack of understanding in the workplace, which may require targeted educational initiatives.

Impact on work/school: A categorical variable.

- **Insights:** This question directly measures the practical impact of PH on a patient's career or education. You can analyse the extent to which the disease forces a change in lifestyle, either partially or totally.

Discussing work/school impact: A multi-select categorical variable.

- **Insights:** This reveals the patient's support network for work-related issues. The data can show if patients are more likely to turn to healthcare professionals, family, or patient organizations for this specific type of support.

Emotional and cognitive impact: These are all Likert scale variables.

- **Insights:** This is a series of questions that measure the emotional and psychological toll of living with a chronic illness. You can create a composite "mental health burden" score or analyse each aspect individually to understand the specific struggles of patients (e.g. isolation, fear, lack of concentration). This is crucial for developing mental health support programs.

Discussing emotional impact: A multi-select categorical variable, similar to Q86.

- **Insights:** This shows who patients trust with their emotional struggles. Comparing this to Q86 might reveal different support networks for different types of problems. For example, a patient might discuss work issues with their PH specialist but emotional issues with a counsellor or family.

Additional comments: A second text/qualitative variable.

- **Insights:** This offers another opportunity for patients to share detailed, unscripted feedback about their emotional and social experiences.

Part 6: Patient association and research involvement

This final part assesses the role of patient organisations and gauges interest in future research.



Membership in patient association: A (Yes/No) variable.

- **Insights:** This simple variable can show the reach of patient associations and the percentage of patients who actively seek support from these groups.

Most useful aspects of an association: A multi-select categorical variable.

- **Insights:** This variable could inform patient organisation strategies by highlighting which services are most valued by members (e.g. peer-to-peer support, financial aid, or informational materials).

Additional comments: A text/qualitative variable.

- **Insights:** This gives patients a chance to suggest new services or areas where patient associations could improve, providing direct feedback for these organisations.

To learn more about this work or make a data request visit...

[Pulmonary Hypertension Global Patient Survey \(PHGPS\) | The Pulmonary Vascular Research Institute \(PVRi\)](#)