



LETTER TO THE EDITOR OPEN ACCESS

Pulmonary Hypertension Global Patient Survey: A Call to Action 2025

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To the Editor,

The first descriptive findings from the adult cohort of the landmark Pulmonary Hypertension Global Patient Survey (PH GPS) were recently published [1]. PH GPS is the largest survey to date to explore the perspectives of patients with PH at a global scale. The survey was devised and project-managed by the Pulmonary Vascular Research Institute's (PVRI) Patient Engagement and Empowerment Workstream (an Innovative Drug Development Initiative Task Force) in collaboration with worldwide patient organizations (appended at the foot of this letter) and included academics, clinicians, patients, and representatives from patient organizations.

Expanding upon previous patient surveys conducted at national [2] or continental [3] levels, PH GPS was an in-depth multi-lingual survey available online in 2023 and 2024. Please refer to the main paper and its supplement for a full description of the methodology and results [1]. In summary, the cleaned final data set consisted of responses from over 3000 adult patients with a diagnosis of any PH group or their proxies from 90 countries and in 22 languages. Themes included diagnostics, treatment, support, quality of life, digital health, and clinical research participation. Further output from PH GPS will be published in due course including the pediatric data set with a separate specific Call to

Action, and plans are evolving for a follow-up PH GPS-2 to understand change over time in addition to regional differences.

The PH GPS Call to Action 2025 evolved following a 12-month period during which the Task Force analyzed the data set through a mixed-methods approach with input from experts in both statistical and qualitative analysis. Methods and interval results were presented at a series of international conferences including the European Respiratory Society (Milan 2023 & Vienna 2024) [4, 5], PVRI (London 2024), and the World Symposium on PH (Barcelona 2024), generating much interest and discussion, and helping to further define the key findings. Through regular Workstream meetings, action points were synthesized from the emerging PH GPS evidence through an iterative and modified Delphi process. By involving all members of the Task Force, the Call to Action was shaped by expert opinion, patients' lived experience, multiple organizations' previous findings, published literature, and clinical guidelines [6]. The aim was to enhance equitable care and research opportunities across regions where PH GPS findings had highlighted geographical disparities.

In this letter, the authors outline 10 key global priorities in the field of adult pulmonary hypertension synthesized from the

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survey's findings. They are presented in the order of the results section of the main paper for ease of cross-referencing [1], not necessarily by priority.

PH GPS Call to Action 2025:

1. Patients should be investigated rapidly to reduce the time to PH diagnosis.
2. Patients should have access to a specialist PH center with diagnostics and therapeutics including genetic testing, parenteral prostacyclins, and mechanical interventions for management of CTEPH.
3. Patient Reported Outcomes Measures (PROMs) should be used to evaluate quality of life and guide holistic care, including psychological and rehabilitative services.
4. Patients should be empowered to engage in shared-decision making in partnership with their clinicians, including managing side effects.
5. Patients with PH should be encouraged to access PH associations by their healthcare professionals for education and other resources.
6. Patients with PH should be assisted in applying to make adjustments to employment or applying for disability support.
7. Patients with PH should be empowered to engage with digital and remote healthcare, where appropriate.
8. Patients with Groups 2, 3, and 5 PH should be better represented in research and specialist clinical care.
9. Patients with PH should be offered the opportunity to participate in clinical research trials and registries, that have ideally been co-designed with patients.
10. Patients and their carers should be invited to participate in PH GPS-2 to evaluate progress over time and further widen representation geographically and in Groups 2 and 3.

The ambition of this endeavor from the outset was to understand and represent the perspectives of patients and relatives with lived experience of PH to better inform and improve their care and outcomes. We encourage stakeholders from around the world to consider how the recommendations apply to their local healthcare settings and population, identifying areas for potential improvement. The Call to Action aims to translate some of the key findings of PH GPS into tangible, goal-directed, quality-improvement objectives to guide future clinical guidelines, healthcare policy, and research priorities.

Author Contributions

Concept and design: all authors. Acquisition, analysis, or interpretation of data: all authors. Drafting of the manuscript: J.N. and J.P.Z. Critical review of the manuscript for important intellectual content: all authors. Supervision: J.P.Z.

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PH GPS Consortium

Name of organization, country/region: A.I.P.I, Italy; Aixike, China; Alliance for Pulmonary Hypertension, Multi-national; A.M.I.P, Italy; AHEPA University Hospital of Thessaloniki, Greece; ANHP, Spain; APHP-Associação Portuguesa de Hipertensão Pulmonar, Portugal; Association for Pulmonary Hypertension Moment Plus Gevgelija, North Macedonia; Association of Citizens suffering from Pulmonary Hypertension (DAH), Bosnia and Herzegovina; Association of Patients with Pulmonary Hypertension in Prague, Czechia; Blue Wings (Plava krila-Udruga pacijenata oboljelih od plućne hipertenzije), Croatia; Bulgarian Society of the patients with pulmonary hypertension (BSPPH), Bulgaria; Centre Hospitalier de Luxembourg, Luxembourg; Chair of international collaboration, South Korean; Chilean Association (HAPCHI), Chile; Clinica Medicala II-Clinical Emergency County Hospital at Targu Mures, Romania, Romania; Dinosaur Trust, UK; Društvo za pljučno hipertenzijo Slovenij, Slovenia; European Lung Foundation, Europe; ERN Lung, Europe; Fundación Contra La Hipertensión Pulmonar España/foundation Against Pulmonary Hypertension Spain, Spain; Gachon University Gil Medical Center, Incheon (Korea (Republic of)), South Korea; HAP Mexico, Mexico; Hipertension pulmonar argentina, Argentina; Hipertensión Pulmonar España (HPE-ORG), Spain; iSEEK/Aixike (Blue Lips), China; Israel Association for Pulmonary Hypertension, Israel; Jenna Lowe Trust, South Africa; Moldavian Association of PH patients, Moldova; Ngha Hospital, Saudi Arabia; Norwegian Association, Norway; PAH Sweden, Sweden; PH Austria and the Lungkids Research Association, Austria; PH Belarus, Belarus; PH Bulgaria, Bulgaria; PHA, USA; PHA Canada, Canada; PHA Europe, Europe; PHA Japan, Japan; PHA Romania, Romania; PHA UK, United Kingdom; PHURDA, Ukraine; Plućna Hipertenzija Srbija, Serbia; Polish Association, Poland; Pulmonālās hipertensijas biedrība, Latvia; Romanian Association, Romania; Samen op adem komen (Breathe together), Belgium; Save and protect, Russia; Stichting Pulmonale Hypertensie, Netherlands; Suomen PAH-potilasyhdistys ry (Finnish PAH Patient Association, Helsinki), Finland; Tüdőér Egylet, Hungary; Ukraine PHA, Ukraine; Združenie pacientov s plúcnou hypertenziou, Slovakia; ŽSPHA Lithuania, Lithuania.

Ethics Statement

The Call to Action is exempt from requiring ethical approval as it is not primary research but an interpretation of existing data.

Conflicts of Interest

The authors declare no conflicts of interest.

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