







Pulmonary Hypertension Global Patient Survey: a preliminary overview

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ABSTRACT

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Background

- Pulmonary hypertension (PH) is caused by a range of conditions affecting people of all ages in diverse ways, with differing treatment options and prognoses.
- Patients' experience of living with PH is likely to vary considerably within and **between countries**, but the extent of this variation is unknown.
- Understanding patients' lived experience of care and research in PH is essential to improving their outcomes.

Aim

• To co-design and deliver the first global patient survey to better inform clinical guidelines and research priorities.

Methods

- Survey drafted via a consensus-building process by a multi-disciplinary panel of collaborators:
 - Patients, PH physicians, nurses, researchers
 - Advocates from Pulmonary Hypertension Associations (PHAs)
- Supported by PVRI and endorsed by ERN-Lung.
- Online survey with over **100 questions** through 3 parallel responder streams:
 - adult patients
 - carers/relatives of adult patients
 - parents/guardians of paediatric patients
- Translated, tested and rolled out in **24 languages** from October 2023 for 2 months.
- **Disseminated by PHAs** via traditional/social media.
- Mixed-methods analysis quantitative descriptive statistics (by region; by PH group) & qualitative thematic analysis.

Results – examples & early highlights Overview Quality of life (all adults with PH) Very often Rarely Often **Sometimes** Sleep difficulties Fidgety / restless / stressed 3770 Angry / frustrated Poor concentration or memory CONTINENTS **COUNTRIES PARTICIPANTS LANGUAGES** Feeling misunderstood Dietary challenges Low self-esteem / confidence Feel isolated / no desire to socialise Fearful / frightened Total responders = 3770 Guilty / embarrassed / hopeless 40% 60% 80% 20% 100% Early drop out = 237 Clinicians/researchers excluded = 10 Responders with discordant year of birth: Time to diagnosis (adults with IPAH & HPAH) Data included = 3464 "adults" age <16 n=6 "children" age ≥16 n=53 >5 years 2-5 years 1-2 years Proxy for adult patients = 439 Proxy for child patient <16y/o = 135 Adult patients = 2890 6-12 months Caregiver = 74 1-6 months Spouse/partner = 173 <1 month Parent = 110 Other = 82Africa TOTAL Central South Asia Central & North Northern Oceania America & n=15 n=11 Europe America Europe **America** Europe n=60 Eastern n=1260 Caribbean n=113 n=263 n=289 n=219 n=64All responses regarding adults = 3329 n=136 n=90 Final adult dataset = 3329 Final paediatric dataset = 135 Other selected highlights Mean age (SD) - 9.4 (4.3) Mean age (SD) - 52.2 (15.9) Female sex - 81.7% Female sex - 54.8% Group 1 - 59.6% 74% 19% Group 1 - 73.3% 20% 60% Group 2 - 13.3% • IPAH - 56.5% of all adult PH of all adult PH of all adult of adults with CHD - 12.2% Group 3 - 2.2% patients have had patients have taken **CTEPH** patients Group 1 PAH Group 4 - 0.7% • CTD - 9.1% negatively impacted have had genetic part in a trial have had PEA • HPAH - 7.0% Group 5 - 1.5% and/or BPA employment Group 2 - 10.7% testing Group 3 - 7.2% MMGroup 4 - 12.5% Group 5 - 3.0%

Conclusions

- The scale and depth of patient-generated data in PH GPS helps to fill the knowledge gap regarding patients' perspectives.
- The results from the survey will inform international clinical guidelines, research priorities and health policy, to improve care and outcomes of patients globally.

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To make a data request and for other information, please go to:

https://pvri.link/phgps





Jeremy Durand: PHA Canada





















