

Pulmonary Hypertension Global Patient Survey: an overview and results



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- 11 Pulmonary Hypertension Associations - global network

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.
- The first global patient survey, co-designed and delivered through an international network, is needed to help improve patient outcomes.

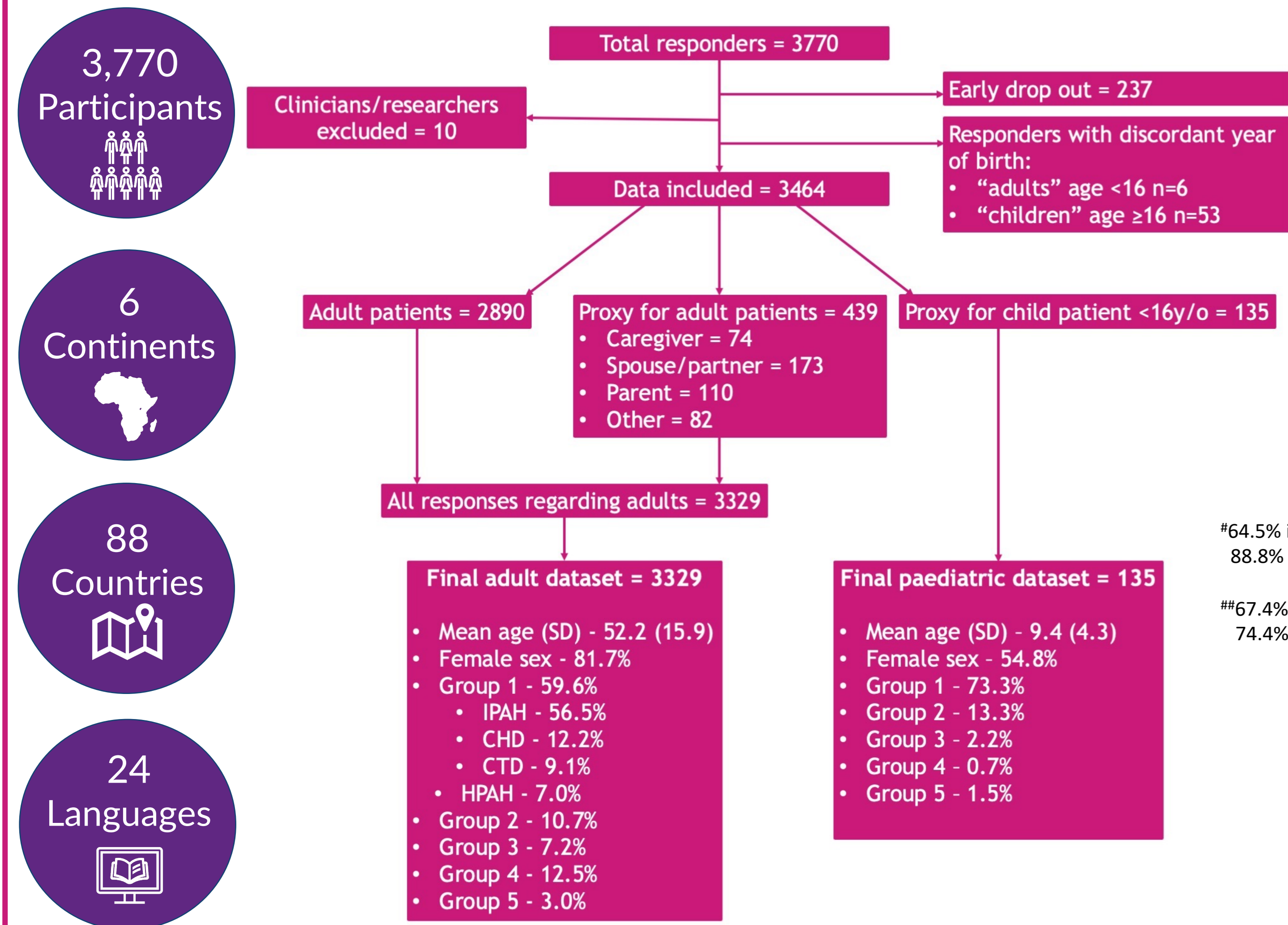
Aim

- To understand patients' lived experience to better inform clinical guidelines & research priorities.

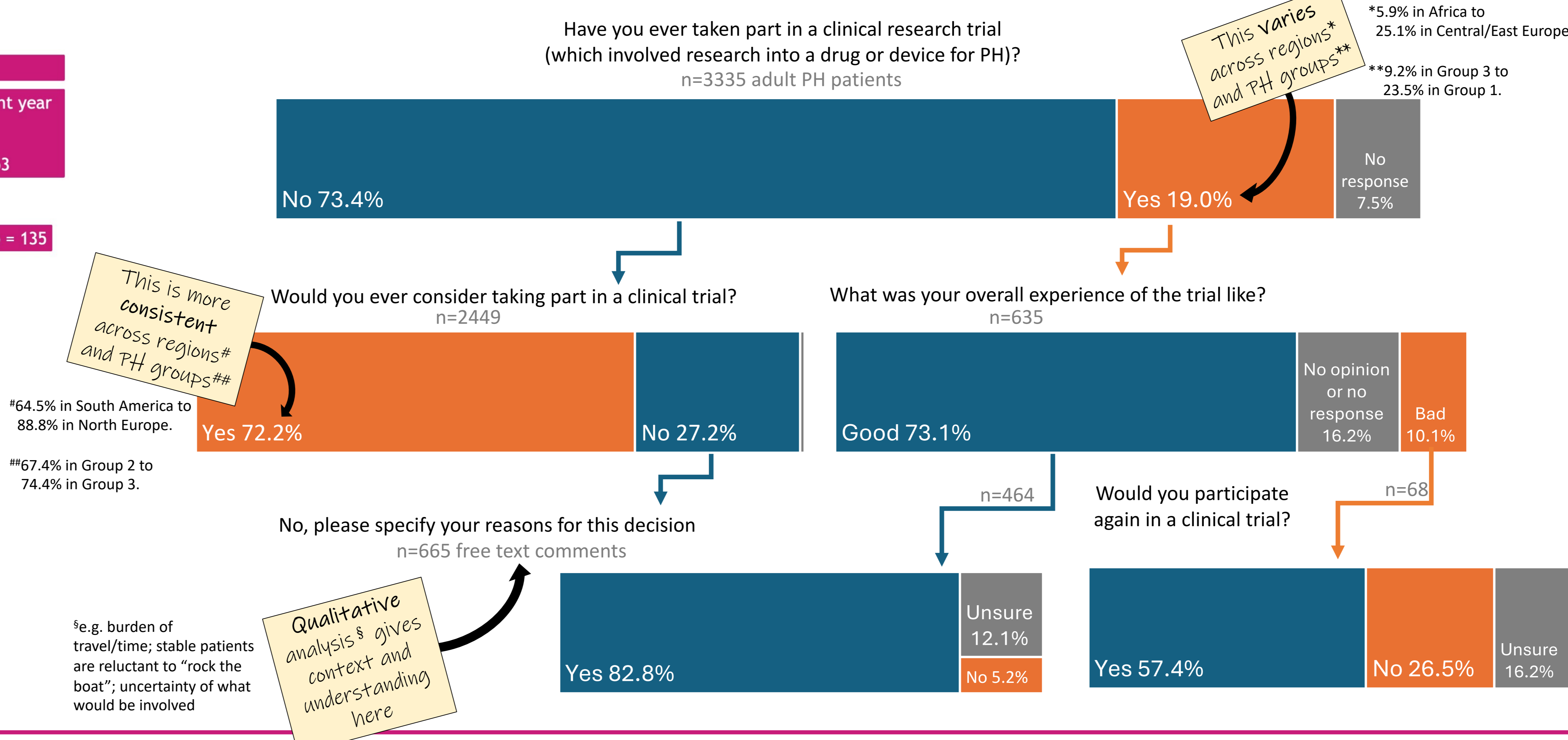
Methods

- Survey drafted via an iterative consensus-building process by a multi-disciplinary panel of collaborators:
 - patients, physicians, nurses, researchers, industry partners
 - advocates from Pulmonary Hypertension Associations (PHAs)
- Themes included time to diagnosis, treatment, quality of life, research participation and digital health.
- Online survey with over 100 questions inclusive of PH Groups 1 to 5 through 3 parallel responder streams:
 - adult patients
 - carers/relatives of adult patients
 - parents/guardians of paediatric patients
- Translated, beta-tested and rolled out in 24 languages from October 2023 for 2 months.
- Disseminated by PHAs via traditional and social media.
- Mixed-methods analysis - quantitative descriptive statistics (by region; by PH group) and qualitative thematic analysis.

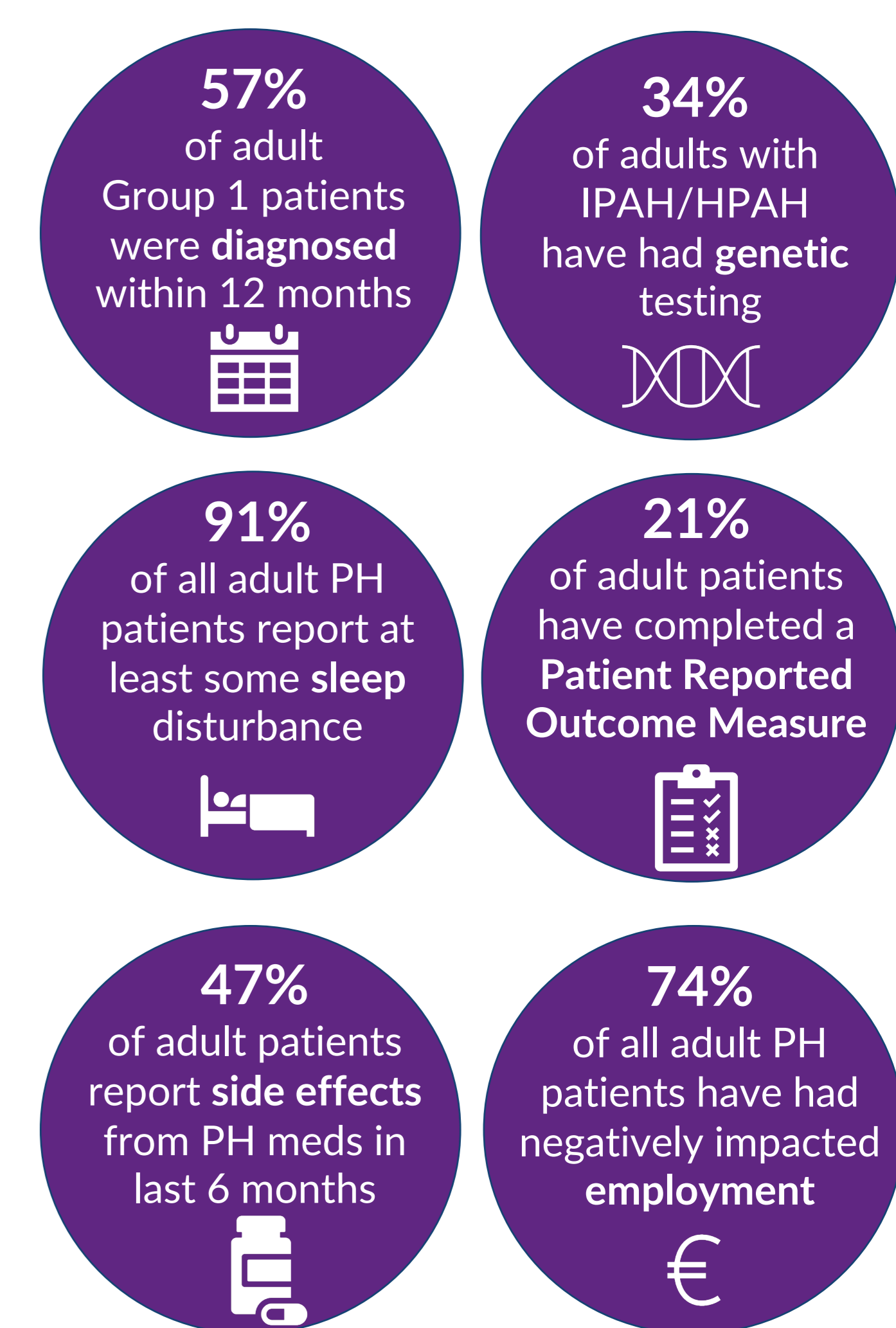
Results - overview



Results - example data regarding clinical trial participation



Results - other highlights

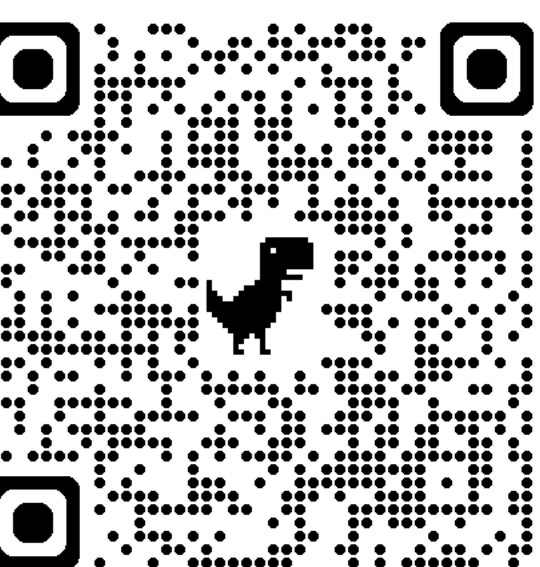


Conclusions

- The scale and depth of patient-generated data in PH GPS helps to fill the knowledge gap regarding patients' perspectives across all PH groups and including paediatrics.
- For example, only a minority (19%) of patients in this global contemporary survey have participated in a PH clinical research trial, but the majority (72%) would engage if invited.
- The results from the survey will inform international clinical guidelines, research priorities and health policy, to improve care and outcomes of patients globally.

To make a data request and for more information, please go to: <https://pvri.link/phgps>

Or email: joseph.newman@nhs.net



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