Pulmonary Hypertension Global Patient Survey:
an overview and results

PHGPS

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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.

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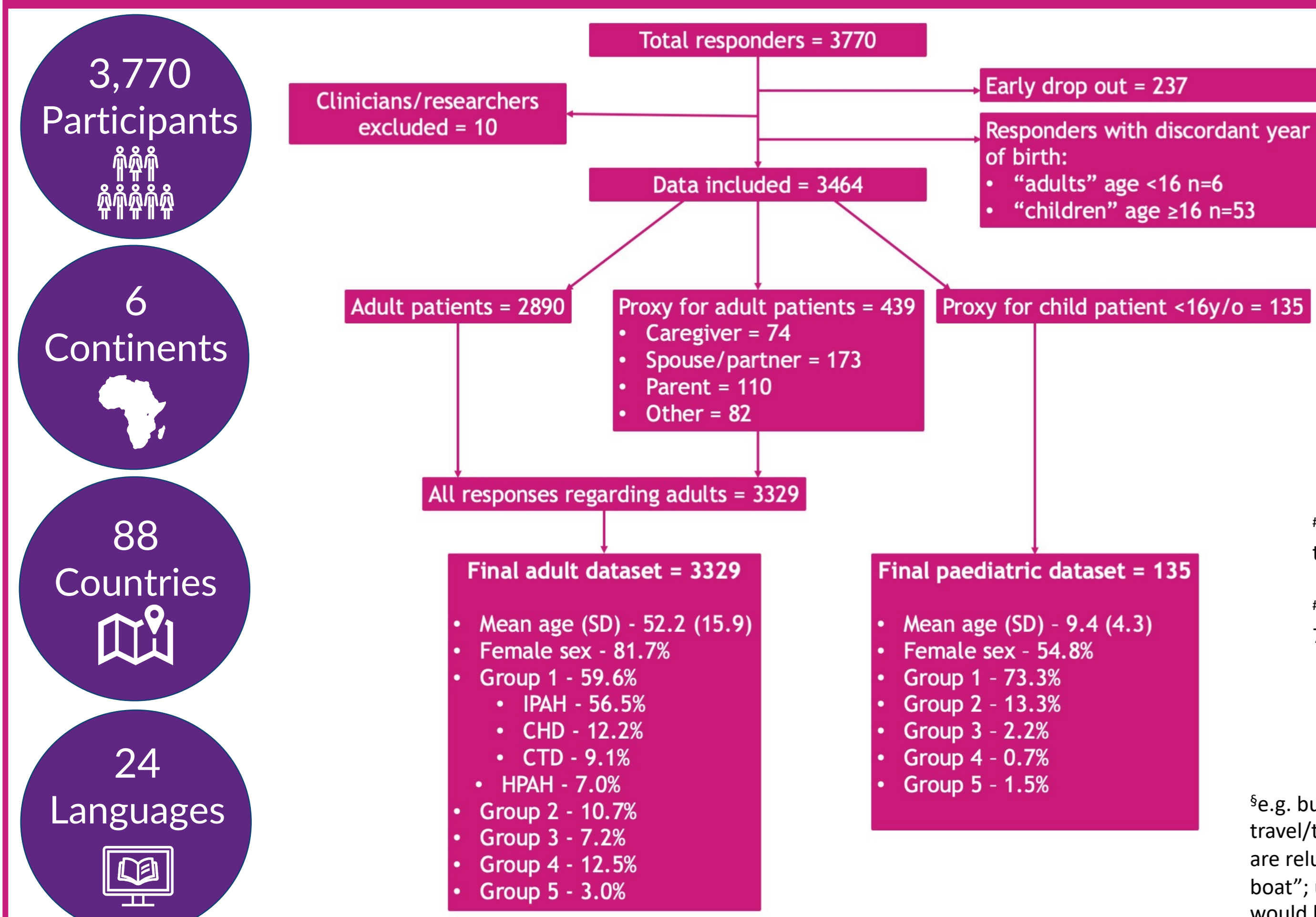
Aim 🎯

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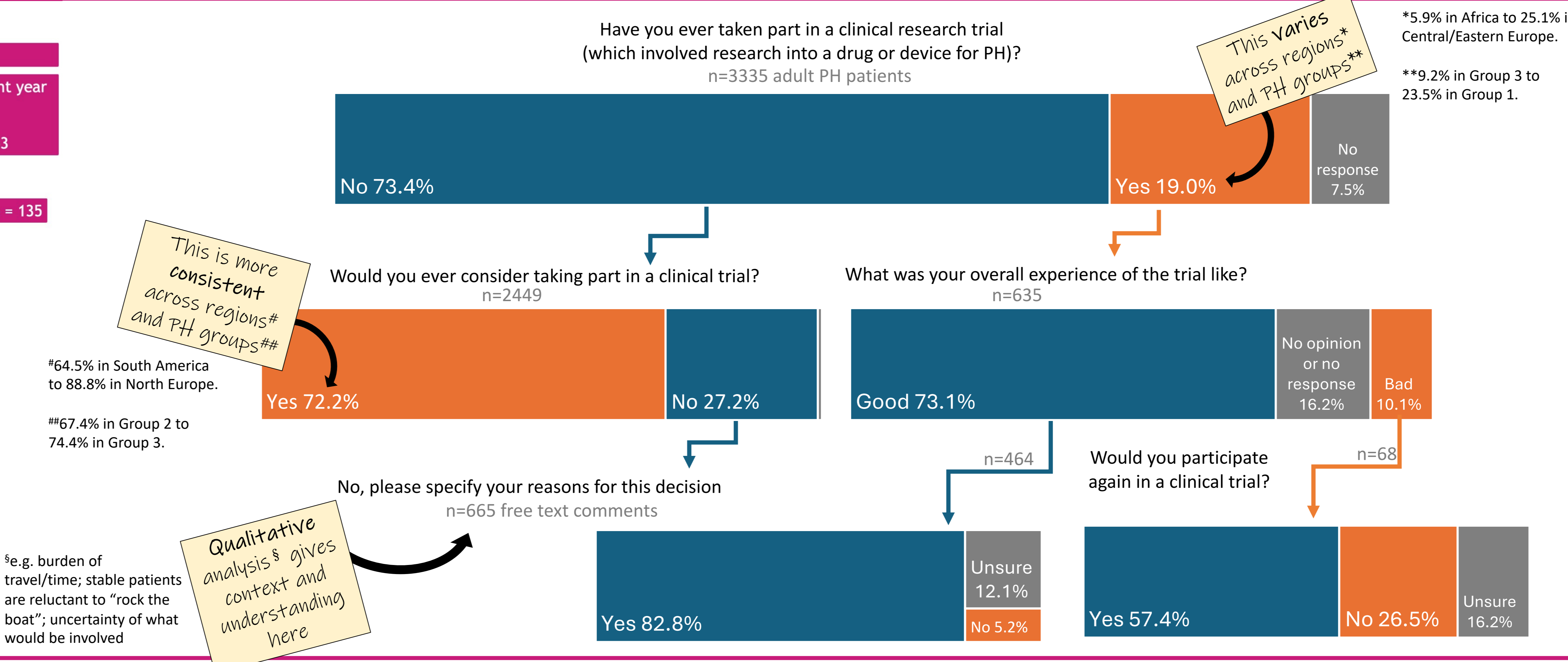
Methods 🔄

- 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.
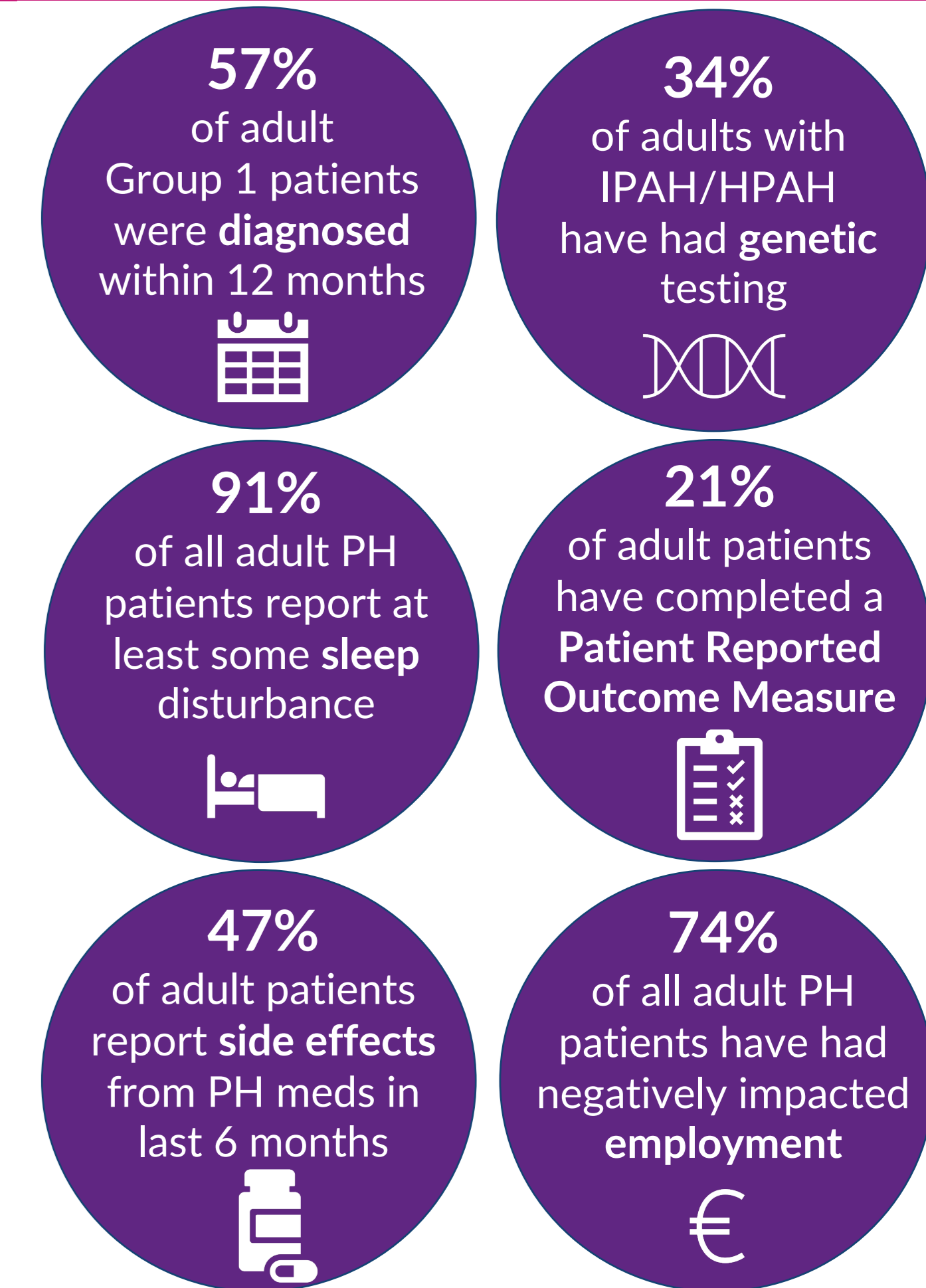
Results – overview 🔭

3,770 Participants

6 Continents

88 Countries

24 Languages

Total responders = 3770

Clinicians/researchers excluded = 10

Early drop out = 237

Responders with discordant year of birth:
- "adults" age <16 n=6
- "children" age ≥16 n=53

Data included = 3464

Adult patients = 2890

Proxy for adult patients = 439
- Caregiver = 74
- Spouse/partner = 173
- Parent = 110
- Other = 82

Proxy for child patient <16y/o = 135

All responses regarding adults = 3329

Final adult dataset = 3329
- Mean age (SD) - 52.2 (15.9)
- Female sex - 81.7%
- Group 1 - 59.6%
  - IPAH - 56.5%
  - CHD - 12.2%
  - CTD - 9.1%
  - HPAH - 7.0%
- Group 2 - 10.7%
- Group 3 - 7.2%
- Group 4 - 12.5%
- Group 5 - 3.0%

Final paediatric dataset = 135
- Mean age (SD) – 9.4 (4.3)
- Female sex - 54.8%
- Group 1 - 73.3%
- Group 2 - 13.3%
- Group 3 - 2.2%
- Group 4 - 0.7%
- Group 5 - 1.5%

Results – example data regarding clinical trial participation 🎲

Have you ever taken part in a clinical research trial (which involved research into a drug or device for PH)?
n=3335 adult PH patients

No 73.4% | Yes 19.0% | No response 7.5%

This varies across regions and PH groups**

*5.9% in Africa to 25.1% in Central/Eastern Europe.
**9.2% in Group 3 to 23.5% in Group 1.

Would you ever consider taking part in a clinical trial?
n=2449

Yes 72.2% | No 27.2%

This is more consistent across regions# and PH groups##

#64.5% in South America to 88.8% in North Europe.
##67.4% in Group 2 to 74.4% in Group 3.

No, please specify your reasons for this decision
n=665 free text comments

§e.g. burden of travel/time; stable patients are reluctant to "rock the boat"; uncertainty of what would be involved

Qualitative analysis§ gives context and understanding here

Yes 82.8% | Unsure 12.1% | No 5.2%

What was your overall experience of the trial like?
n=635

Good 73.1% | No opinion or no response 16.2% | Bad 10.1%

Would you participate again in a clinical trial?
n=464 ... n=68

Yes 57.4% | No 26.5% | Unsure 16.2%

Results – other highlights ⭐⭐

57% of adult Group 1 patients were **diagnosed** within 12 months 📅

34% of adults with IPAH/HPAH have had **genetic** testing 🧬

91% of all adult PH patients report at least some **sleep** disturbance 🛏

21% of adult patients have completed a **Patient Reported Outcome Measure** 📋

47% of adult patients report **side effects** from PH meds in last 6 months 💊

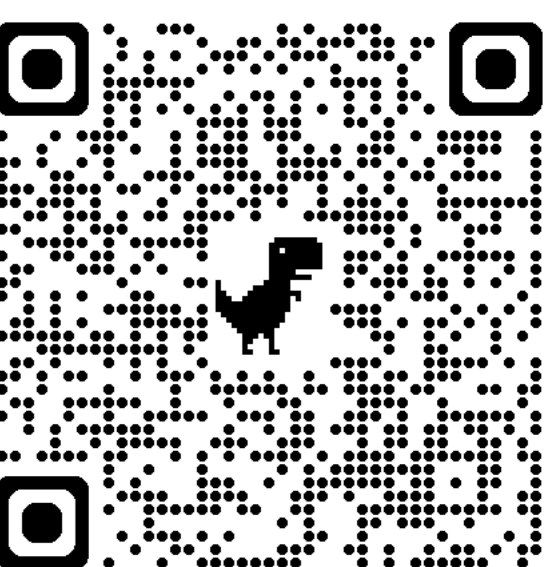**74%** of all adult PH patients have had negatively impacted **employment** €

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.
- Only a minority (19%) of patients in this global contemporary survey have been offered the opportunity to participate in trials, 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:
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