PHGPS

7th WORLD SYMPOSIUM ON PULMONARY HYPERTENSION

Pulmonary Hypertension Global Patient Survey: a preliminary overview

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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 & prognoses

- Patients' experience of living with PH is likely to vary considerably within & **between countries**, but the extent of this variation is unknown

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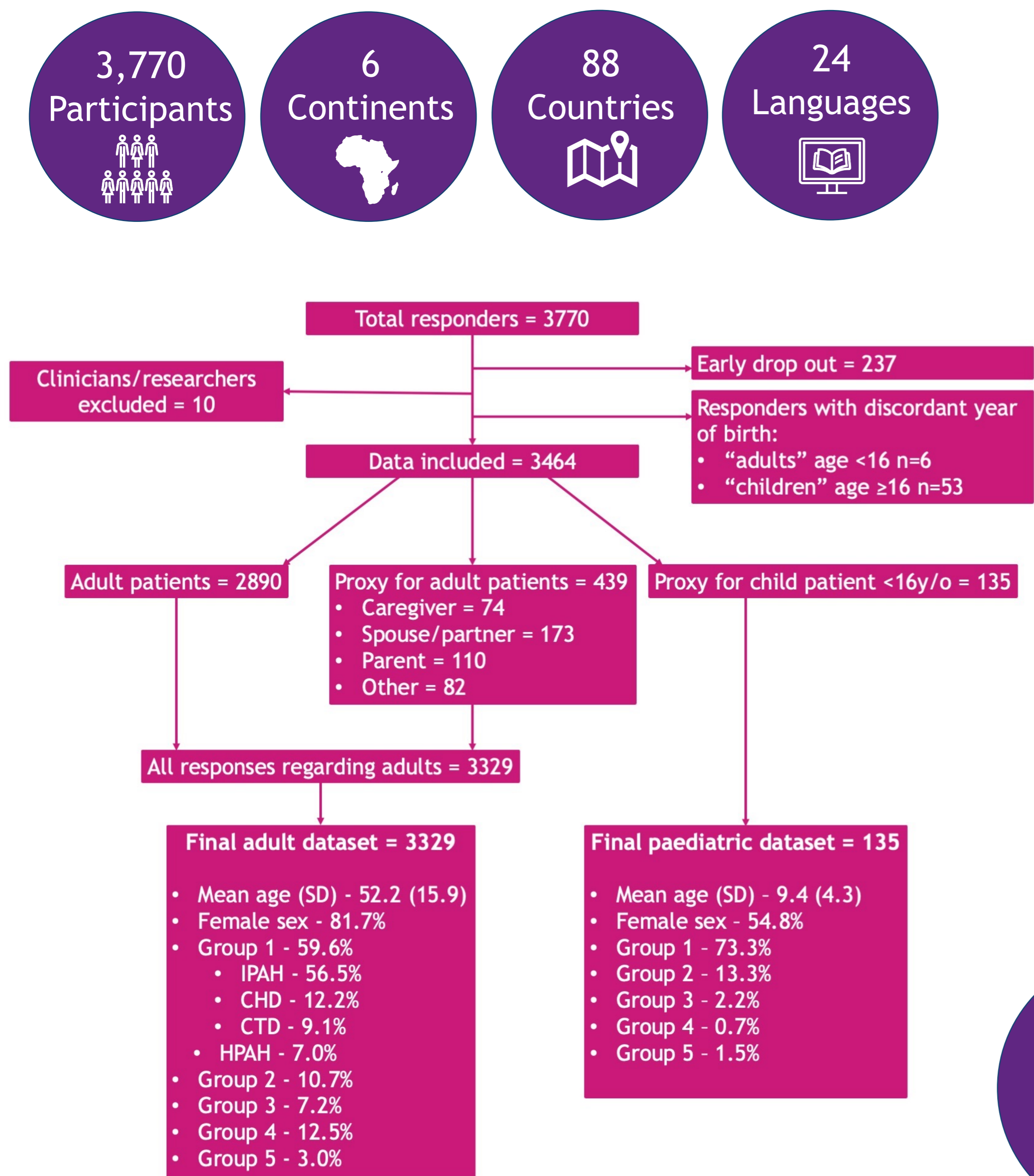
Aim

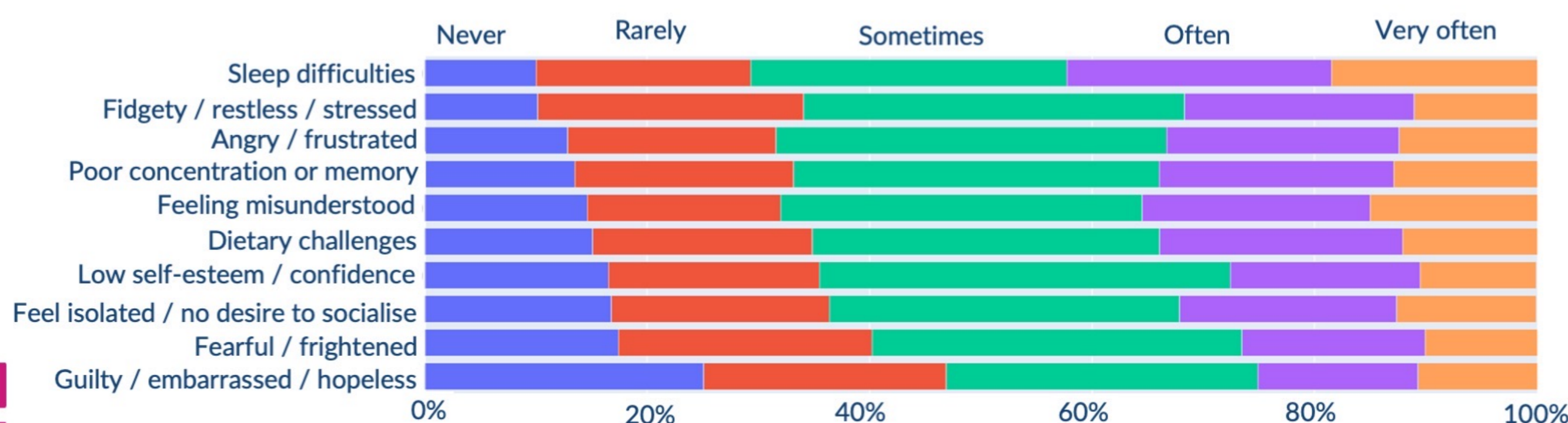- To **understand patients' lived experience** to better inform clinical guidelines & research priorities

Methods

- Survey drafted via a consensus-building process by a **multi-disciplinary panel** of collaborators
  - **patients**, physicians, nurses, researchers, industry partners
  - advocates from Pulmonary Hypertension Associations (PHAs)
- Supported by PVRI & 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 & 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
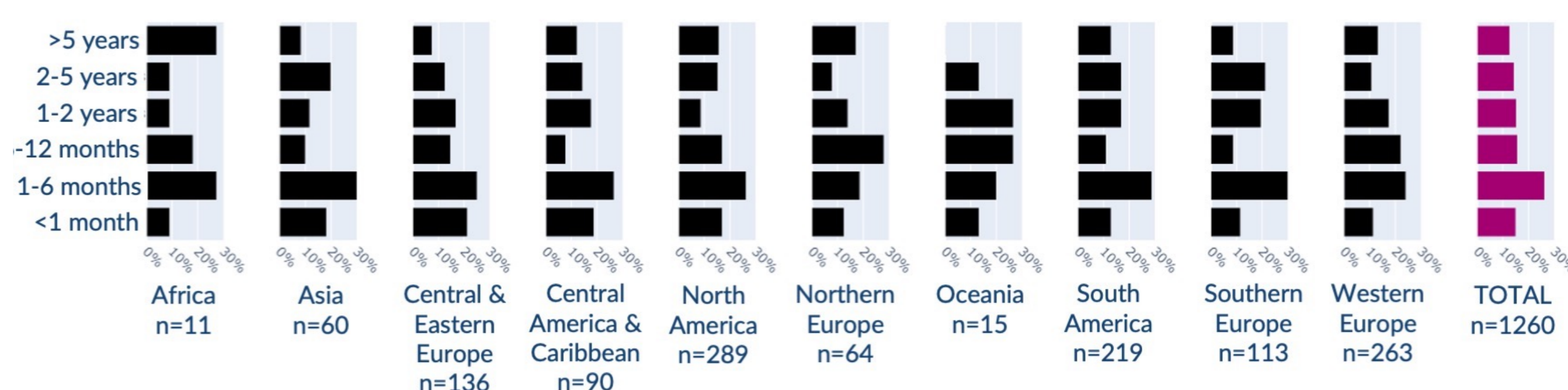
Results – examples & early highlights

- **3,770** Participants
- **6** Continents
- **88** Countries
- **24** Languages

Quality of life (all adults with PH)

Categories: Never, Rarely, Sometimes, Often, Very often
- Sleep difficulties
- Fidgety / restless / stressed
- Angry / frustrated
- Poor concentration or memory
- Feeling misunderstood
- Dietary challenges
- Low self-esteem / confidence
- Feel isolated / no desire to socialise
- Fearful / frightened
- Guilty / embarrassed / hopeless

Axis: 0%, 20%, 40%, 60%, 80%, 100%

Flow diagram

- 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%

Time to diagnosis (adults with IPAH & HPAH)

Categories: >5 years, 2-5 years, 1-2 years, -12 months, 1-6 months, <1 month

Region	n
Africa	n=11
Asia	n=60
Central & Eastern Europe	n=136
Central America & Caribbean	n=90
North America	n=289
Northern Europe	n=64
Oceania	n=15
South America	n=219
Southern Europe	n=113
Western Europe	n=263
TOTAL	n=1260

- **20%** of adults with Group 1 PAH have had genetic testing
- **19%** of all adult PH patients have taken part in a trial
- **60%** of all adult CTEPH patients have had PEA and/or BPA
- **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
- 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 other information, please go to
https://pvri.link/phgps