

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

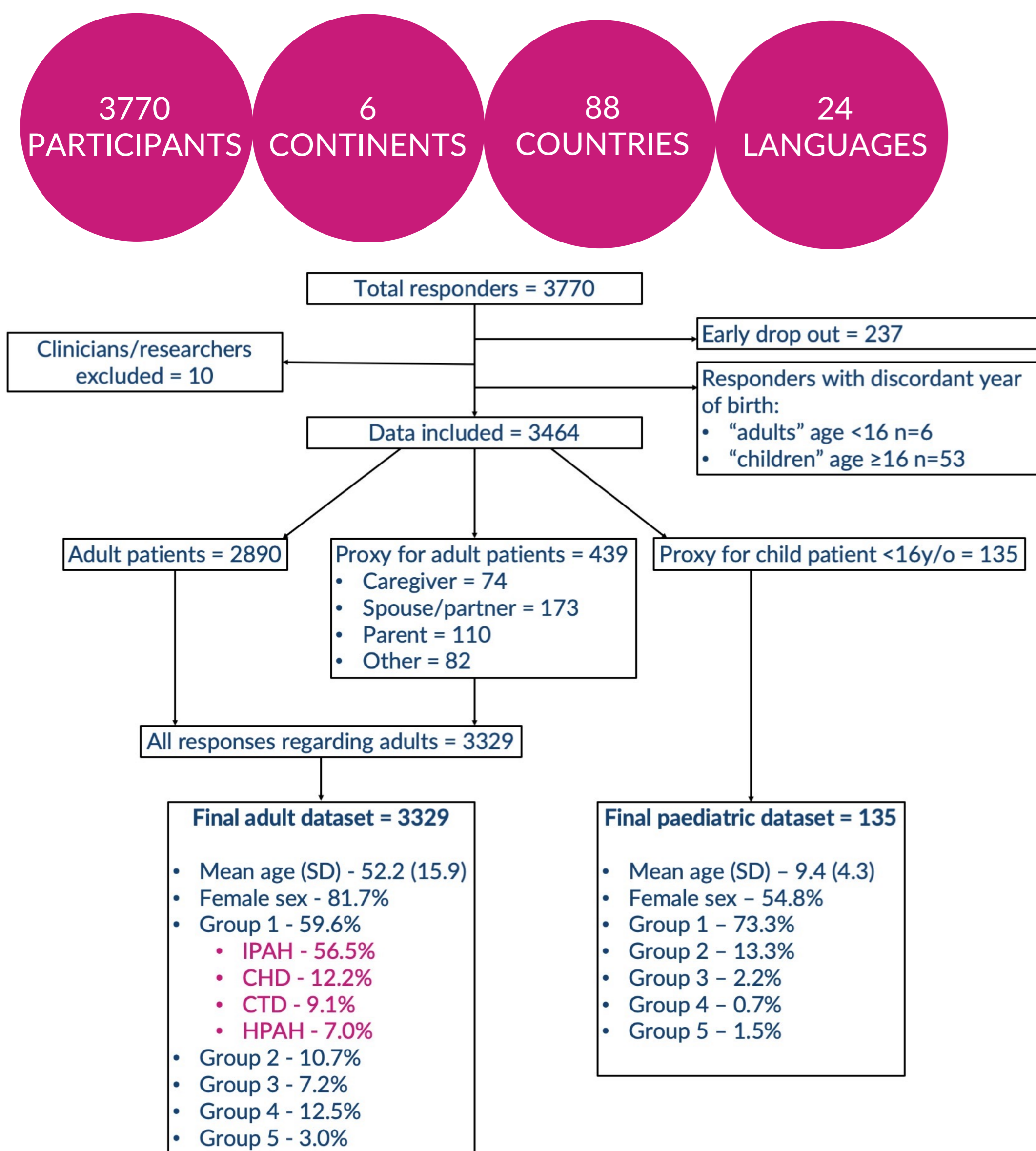
- To co-design and deliver **the first global patient survey** to better inform clinical guidelines and research priorities.

Methods

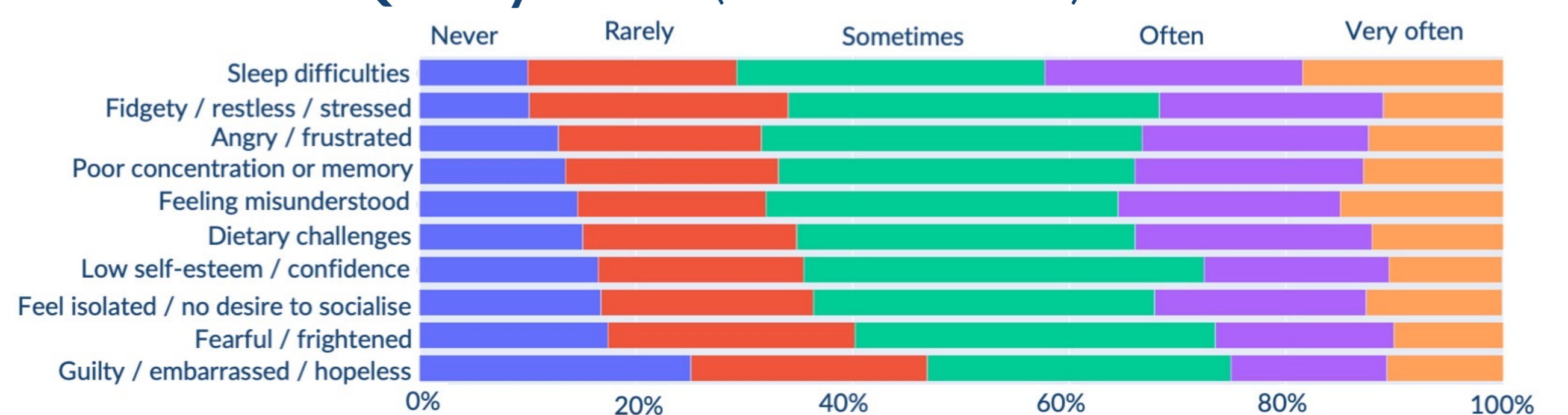
- Survey drafted via a consensus-building process by a **multi-disciplinary panel of collaborators**:
 - Patients, PH physicians, nurses, researchers
 - Advocates from Pulmonary Hypertension Associations (PHAs)
- Supported by PVRI and endorsed by ERN-Lung.
- Online survey with over **100 questions** 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

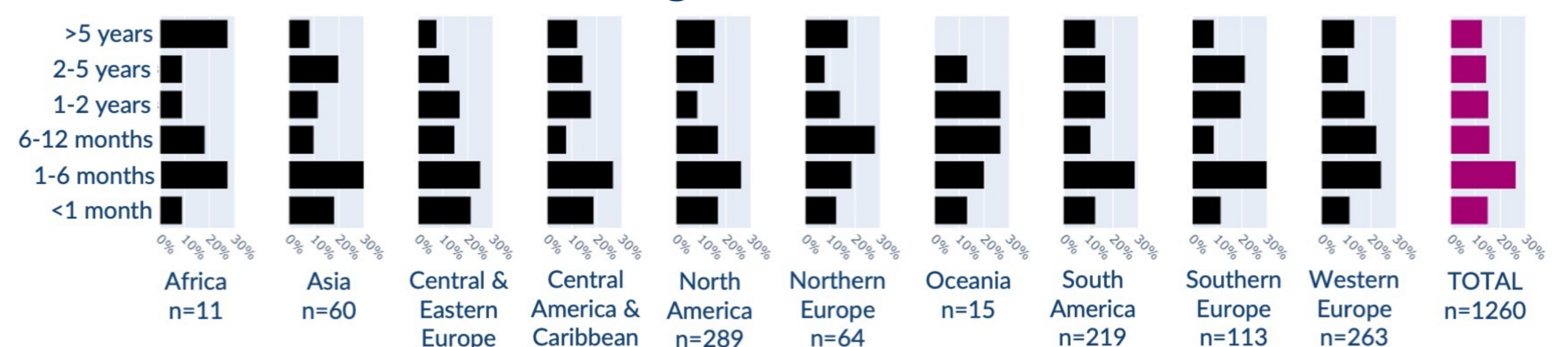
Overview



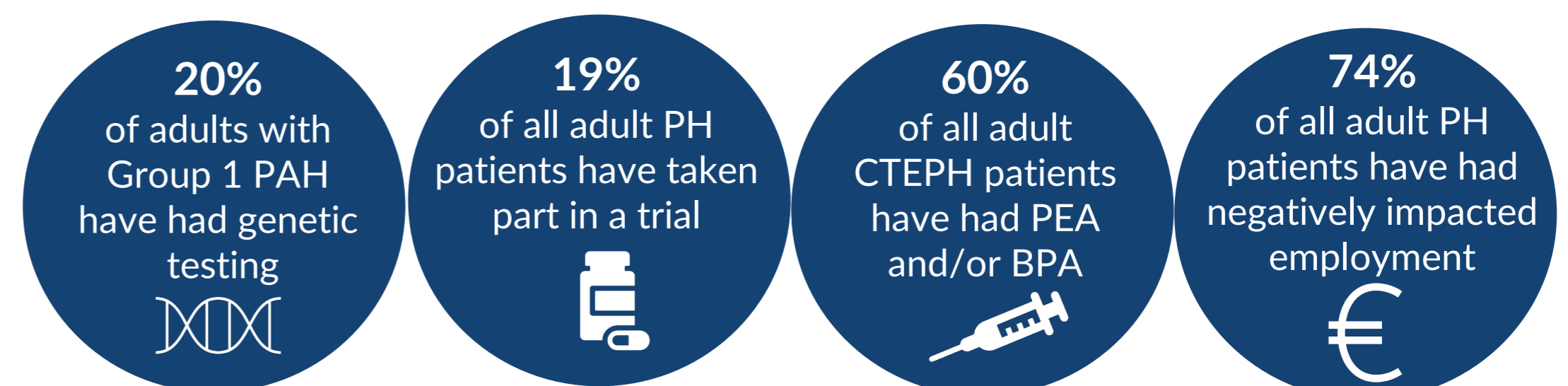
Quality of life (all adults with PH)



Time to diagnosis (adults with IPAH & HPAH)



Other selected highlights



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.**

With thanks to all patients, relatives and caregivers who have participated, and our many collaborators including:

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Tess Jewson: Patient Representative
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Wendy Gin-Sing: Nurse Consultant

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

<https://pvri.link/phgps>

