SUMMARY

PH Global Patient Survey on Patient Experiences and Perspectives

The Pulmonary Vascular Research Institute (PVRI) published results from the Pulmonary Hypertension Global Patient Survey, presenting data from 3329 adult patients or their proxies from 90 countries.

These data illustrate the experiences and thoughts of PH patients worldwide, although the Global South, and PH Groups 2 and 3, continue to be underrepresented.

The data had six main themes:

1. ## Access to specialist healthcare

   Globally, about half of pulmonary arterial hypertension (PH Group 1) and chronic thromboembolic pulmonary hypertension (PH Group 4) patients are diagnosed within a year.
   Four fifths of adult responders reported being under the care of a PH specialist centre.
   Travelling to their PH centre (at least once a year) most often happened by car. Both distance and time were substantial: on average, PH clinics were more than 50 km away, and half of patients travelled more than an hour each way.
   Two-thirds of patients found attending their appointments difficult or stressful to some degree.
   Four in five patients feel that that they fully understand the information provided to them, however, nearly half found how they felt did not always match their medical results.

2. ## Health-related quality of life

   Patients noted slight improvements in their symptoms since diagnosis, but three-quarters of responders said PH negatively affected their employment or education. Only two in five felt they were physically active.
   Nearly half of patients reported side effects due to PH medications in the six months before the survey, most commonly nausea, but only a third of those experiencing side effects discussed possibly changing medications with their healthcare provider. Responders did discuss negative impacts on their wellbeing with their PH specialist, family or friends, or life partner.

3. Patient Reported Outcome Measures (PROMs)

Only one in five responders reported ever completing Patient Reported Outcome Measures. Of those few, only a quarter received feedback from their PH team and only 7% felt the management of their PH had been changed based on their PROM responses.
PROMs continue to be under-used despite advocacy, previous survey findings, and international guidelines.

4. Self-monitoring and digital health

Seven in ten reported all their appointments were in person, but eight in ten were willing to have some aspects of care delivered remotely.
Nearly all adult PH patients under 70 own a smartphone. After 70, smartphone ownership declines.
Half of patients monitor their health status. Of those who do, half use paper or a calendar and more than a quarter use an app on their smartphone.
Half of patients monitor their physical activity. Of those who do, about two-thirds use a smartwatch and the rest use their phone.
Seven in ten patients already share their self-collected information with their clinical team. Most of the rest would be willing to do so.

5. Disability and support

Just over half of PH patients were officially registered as disabled. Of those, about two thirds received parking benefits, two in five received financial support, and fewer than one in five received enhanced care support. Rehabilitation was available for two in five responders, but an equal number were unsure.
Over half of responders were part of a national patient PH organisation, where the most useful perceived areas of support included information/education, patient meetings/support groups, informative website, and awareness activities.

6. Participating in research

Three quarters of PH patients had not participated in any clinical research trials, but three-quarters of those who had not participated would consider doing so if asked.
Of those who had participated in clinical trials, three-quarters had good experiences and four-fifths were willing to participate again, especially if their initial experience was good.
Nine in ten responders would be willing to allow researchers to access and use their anonymised healthcare data that had already been collected as part of routine clinical care.

Regional variations

Patients' responses varied across the ten geographical regions.

North America

- (No highs or lows)

Central America & Caribbean

- Lowest proportion of adult responders reporting being under the care of a PH specialist centre

South America

- Lowest willingness to take part in clinical trials

Central and Eastern Europe

- Highest participation in clinical research trials

North Europe

- Highest willingness to take part in clinical trials

Southern Europe

- Highest improvement in symptoms after diagnosis

Western Europe

- Highest partial or full financial coverage of PH healthcare costs

Asia

- Highest distance travelled to receive care from a PH centre
- Lowest partial or full financial coverage of PH healthcare costs

Africa

- Lowest improvement in symptoms after diagnosis
- Lowest participation in clinical research trials

Oceania

- Highest proportion of adult responders reporting being under the care of a PH specialist centre
- Lowest distance travelled to receive care from a PH centre

What's next?

Trends show that patients are willing to innovate in clinical research and digital health and to take charge of their wellbeing, although PROMs continue to be under-used.