

The Importance of Pulmonary Hypertension Associations: Results from the Pulmonary Hypertension Global Patient Survey (PH GPS)

AUTHORS

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BACKGROUND

Pulmonary hypertension associations provide critical education, support and empowerment for patients. However, the global reach and utility of PHAs remain unclear.

METHODS

The PH Global Patient Survey included questions on PHA membership and services. It surveyed adult and pediatric patients and caregivers across all PH groups. Dissemination relied on PHA media channels.

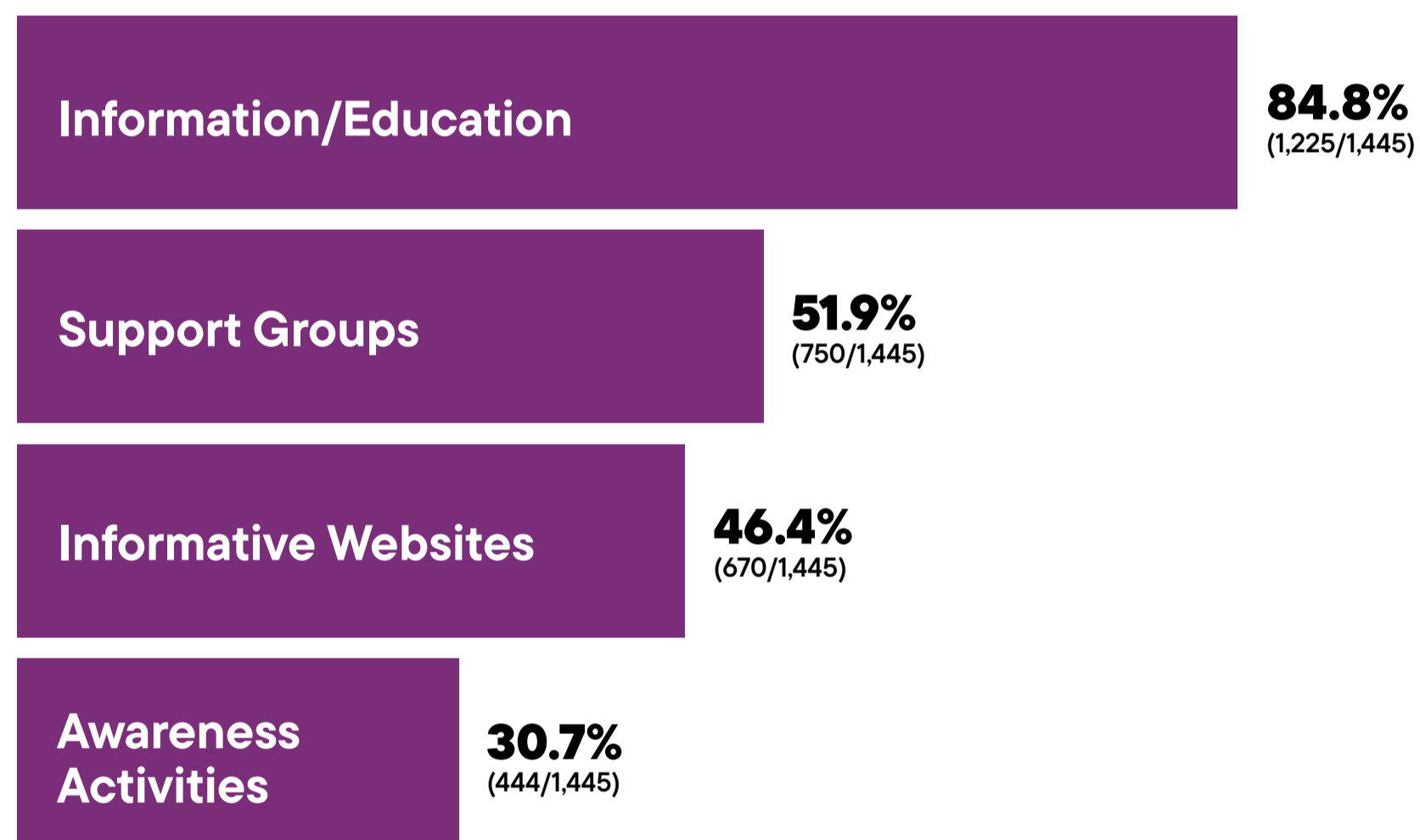
RESULTS

Participation in PH Associations

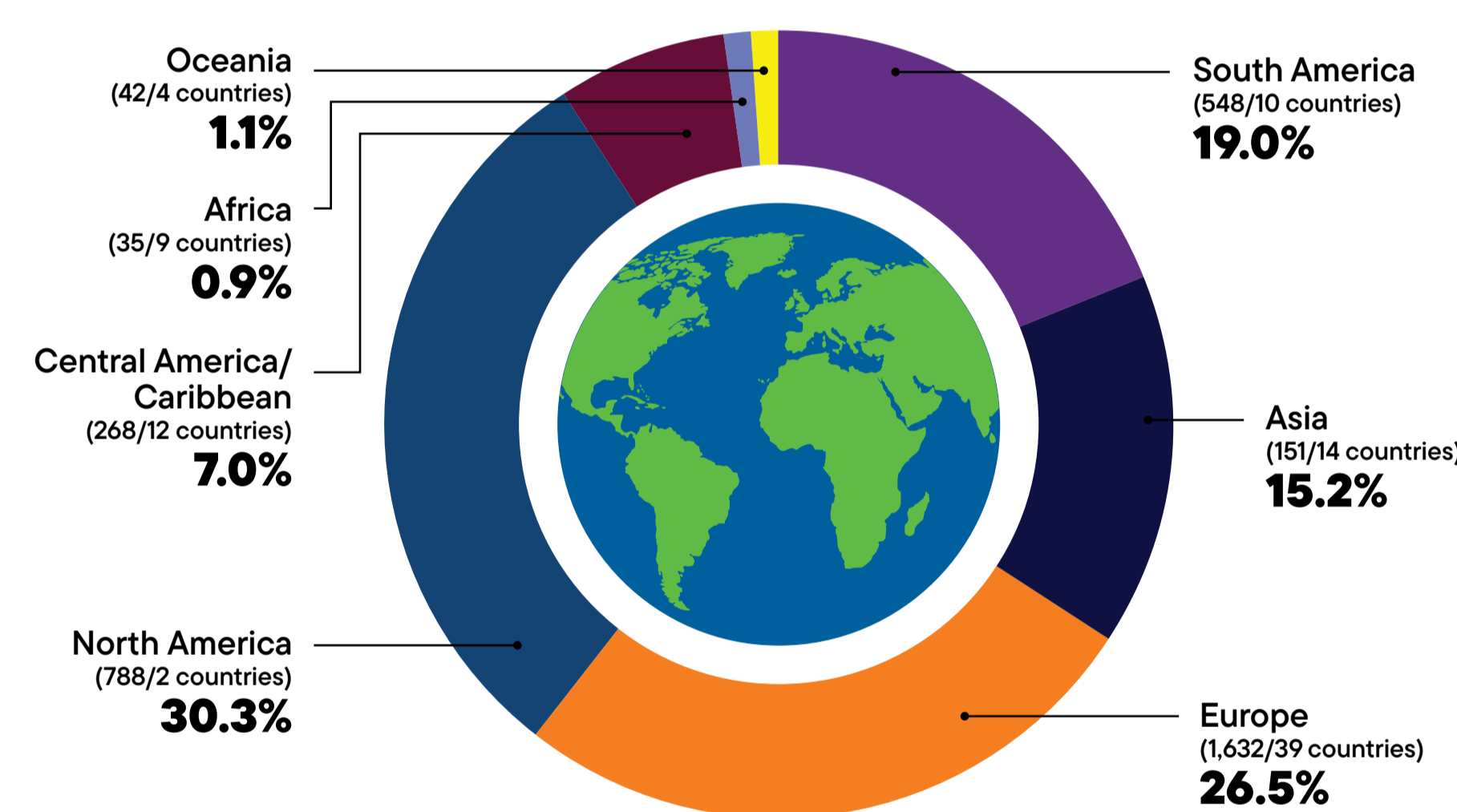
- 54.8% (1,445/2,638) reported membership.
- Likely overestimated among the wider PH population due to survey dissemination methods.



Most Useful PH Association Services as Reported by Survey Respondents



Geographic Distribution of Survey Respondents



Additional Benefits Reported

- Sense of community and purpose.
- Practical support (e.g., legal aid, financial help).
- Gateway to clinical trials.

Qualitative Insights

PHAs often provide emotional support and advocacy. Support needs vary by healthcare context:

- **Developed regions:** Focus on education and social support.
- **Developing regions:** Emphasis on medication access and financial assistance.

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GREATEST VALUE OF PH ASSOCIATIONS

“A sense of community and belonging, not feeling alone with a (often invisible) disease which can feel isolating.”

“Feeling useful by giving support to others who are earlier on in their PH journey/newly diagnosed.”

“Organising fundraisers to advance research and for awareness raising campaigns.”

CONCLUSIONS

Pulmonary hypertension associations are essential for PH patient education and support, but they are underutilized. Health care providers should proactively direct all patients to PHAs to maximize patient empowerment.