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Supporting unmet needs of patients with pulmonary hypertension and their caregivers - think big but act local!

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Background: A multinational survey was performed in 2023 to better understand the needs of patients with pulmonary hypertension and their caregivers. Here we present unmet needs reported in the survey with a focus on country specific differences.

Methods: Patient organizations from nine European countries (Germany, Italy, Austria, Spain, Sweden, Poland, Hungary, Czech Republic, Slovakia) invited their members to complete the online survey.

Results: 619 surveys were completed (527 patients, 92 caregivers). Top three contributing countries were Germany, Italy and Austria with 117 (18,9%), 88 (14,2%) and 87 (14,1%) participants. While there is a high unmet need for support to improve quality of life in all participating countries, but above all in Germany and Poland, we observed pronounced country differences (range 50 – 71%). Unmet needs of patients differ country by country also for exercise and nutrition advice and very markedly also for rehabilitation advice (range 9 – 51%). We have already reported the unmet needs of caregivers differ from those patients report, especially with the need for psychological support expressed by caregivers. However also here we observed huge differences, as only 18% of Swedish caregivers consider this an unmet need compared to 64% and 67% in Poland and Hungary respectively.

Conclusion: Our results indicate that support programs for pulmonary hypertension need to be tailored according to the local needs of patients and their caregivers. A deep understanding of country-specific needs and challenges is essential, underlining the importance of local patient organizations and their involvement in European support projects.

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