

An insight into the participation of patients affected by pulmonary hypertension in research

30 million people are living with a rare disease in Europe and 300 million worldwide

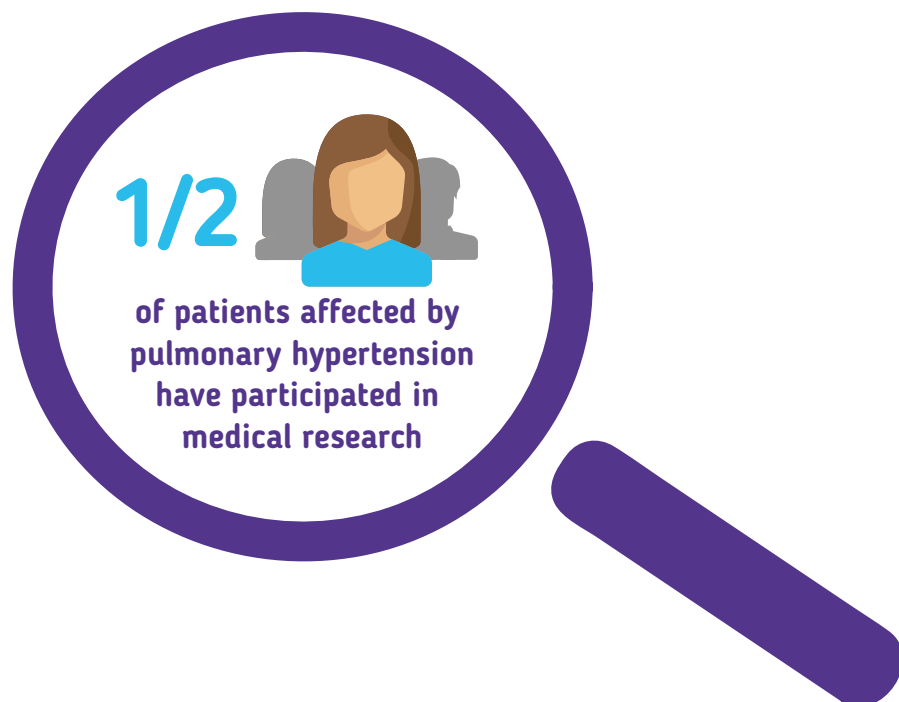


No cure for the vast majority of diseases and few treatments available

30 patients and their families affected by pulmonary hypertension responded to the survey, conducted in 23 languages across 42 countries worldwide

Key findings of a Rare Barometer Voices survey on the participation of patients affected by pulmonary hypertension in research:

Have patients participated in research?



Top 3 obstacles to rare disease research

Small patient population

Lack of public funding

Insufficient dialogue



Rare Barometer Voices is a EURORDIS-Rare Diseases Europe online survey initiative. It brings together over 8,000 patients, carers and family members to make the voice of the rare disease community stronger.

Thank you to all Rare Barometer Voices participants and partners! To read the full report, register to participate in future surveys or for more information, visit: eurordis.org/voices