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

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

**Have patients participated in research?**

1/2 of patients affected by pulmonary hypertension have participated in medical research

**Top 3 obstacles to rare disease research**

1. Small patient population
2. Lack of public funding
3. Insufficient dialogue

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

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