An insight into the participation of patients affected by rare and complex epilepsies in research

Key findings of a Rare Barometer Voices survey on the participation of patients affected by rare and complex epilepsies in research:

What type of research do patients participate in?

1/3 of patients affected by rare and complex epilepsies have participated in medical research, among them:

- 46% to develop treatments & therapies
- 33% in research on quality of life
- 17% to develop genetic therapies

Top 3 obstacles to rare disease research:

- Lack of public funding
- Lack of private funding
- Insufficient dialogue between scientists, patients and clinicians

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

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.