An insight into the participation of rare disease patients in research

Key findings of a Rare Barometer Voices survey on the participation of rare disease patients in research:

Top 3 obstacles to rare disease research:
1. Lack of public funding
2. Lack of private funding
3. Small patient population

Top 3 priorities for patients:
1. Develop therapies
2. Improve diagnosis
3. Identify mechanisms & causes of rare diseases

What type of research do patients participate in?
- 59% to develop treatments & therapies
- 52% in research on quality of life
- 16% to develop genetic therapies

What matters to patients?
- Participating in research to help science & the community
- Receiving clear information about the research project
- Having a quality relationship with the researchers

1/3 of rare disease patients have participated in medical research, among them:

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.