An insight into the participation of patients affected by a rare bone disease 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
82 patients and their families affected by a rare bone disease 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 a rare bone disease in research:

What type of research do patients participate in?

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

- 50% to develop treatments & therapies
- 46% in research on quality of life
- 12% to develop medical devices

Top 3 obstacles to rare disease research:

1. Lack of public funding
2. Lack of interest of researchers in rare diseases
3. Small patient population

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.