

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

Lack of public funding

Lack of interest of researchers in rare diseases

Small patient population



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