An insight into the participation of patients affected by a rare cancer 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

117 patients and their families affected by a rare cancer 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 cancer in research:

What type of research do patients participate in?

- 59% in research on quality of life
- 31% to develop treatments & therapies
- 7% to develop genetic therapies

Top 3 obstacles to rare disease research:

1. Lack of public funding
2. Insufficient dialogue between scientists, patients and clinicians
3. Lack of interest of researchers

1/4 of patients affected by a rare cancer have participated in medical research, among them:

- 59% in research on quality of life
- 31% to develop treatments & therapies
- 7% to develop genetic therapies

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.