

# An insight into the participation of rare disease patients 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

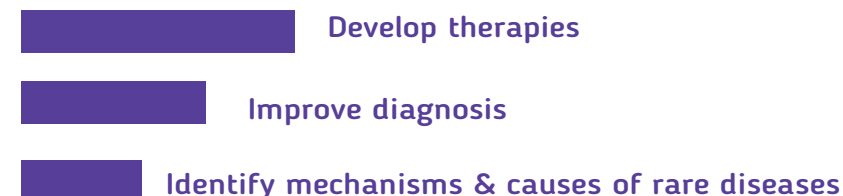
**3213** rare disease patients and their families responded to the survey, conducted in 23 languages across 42 countries worldwide

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

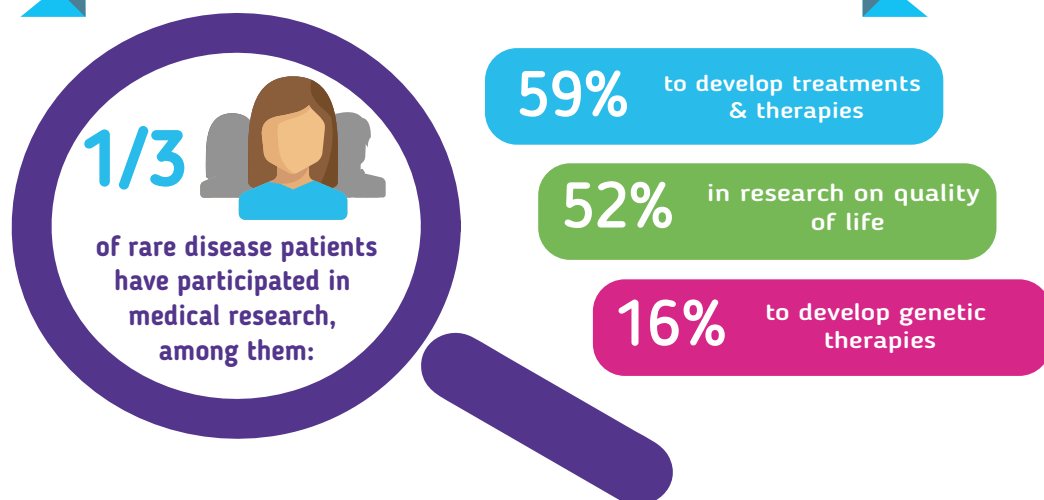
### Top 3 obstacles to rare disease research



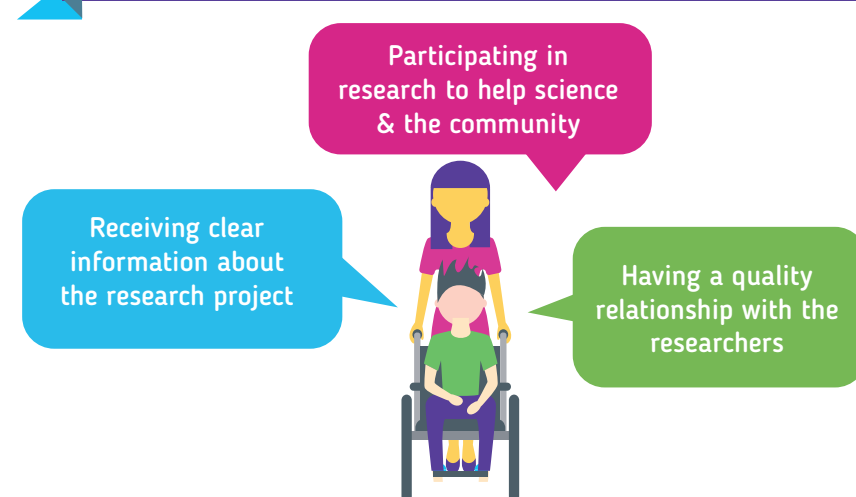
### Top 3 priorities for patients



### What type of research do patients participate in?



### What matters to patients?



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](http://eurordis.org/voices).