

## Rare Barometer Voices goes global!

**1 September 2017, Paris** – [Rare Barometer Voices](#), the EURORDIS survey tool that collects the opinions of rare disease patients, families and carers, is now open to participants around the world. Formerly available to participants in Europe, Rare Barometer Voices is now available in all countries\*. Surveys are conducted in 23 languages\*\*.

### [Register here](#) to take part in surveys on issues that matter to you!

Sandra Courbier, Surveys and Social Research Manager at EURORDIS and Rare Barometer Leader, commented, *"With over 6,000 voices from across Europe already registered, we are delighted that participants from around the world can now participate in Rare Barometer Voices surveys."*

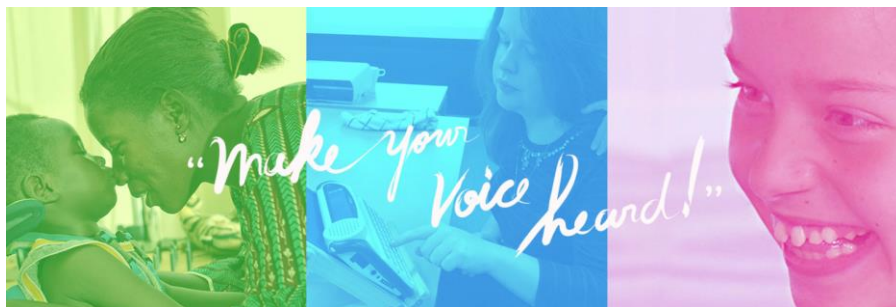
She added, *"Results from surveys on issues such as people's everyday lives, their participation in research and their opinions on data protection are collected and used in our advocacy work and the advocacy work of our members; by growing Rare Barometer Voices, we are able to ensure that results truly reflect the voice of the rare disease community around the world."*

Survey results will be made available to Rare Barometer Voices participants and EURORDIS member patient organisations in order to feed advocacy work of the rare disease community. Results from Rare Barometer Voices surveys will also now support the advocacy of other EURORDIS initiative [Rare Diseases International](#), the global alliance of people living with a rare disease of all nationalities across all rare diseases.

## Share your opinions & experiences of rare disease research

[Register for Rare Barometer Voices](#) wherever you are in the world to participate in the latest survey on **rare disease research**, the theme for [Rare Disease Day 2018](#).

[Respond to the survey](#) to share your experience of participating in rare disease research and let us know what you think are the main obstacles to rare disease research. The results will inform the advocacy work and activities of patient organisations involved in Rare Disease Day 2018.



###

## Rare Barometer Voices

Rare Barometer Voices is a tool used to carry out EURORDIS quantitative surveys on issues affecting people living with a rare disease. It is made up of a community of over 6,000 people who participate in surveys and studies. The Rare Barometer Voices survey software enables high-quality, secure data collection and analysis.

Rare Barometer Voices is a EURORDIS-Rare Diseases Europe initiative and part of the wider [Rare Barometer Programme](#), created to systematically collect patients' opinions on transversal topics and introduce them into the policy and decision-making process. The objective is to transform patients' and families' opinions and experiences into figures and facts that can be shared with a wider public and policymakers.

## EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 700 rare disease patient organisations from more than 60 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services. Follow [@eurordis](#) or see the [EURORDIS Facebook page](#). For more information, visit [www.eurordis.org](http://www.eurordis.org).

\*All United Nations member countries.

\*\*Rare Barometer Voices surveys are conducted in the versions of languages (English from United Kingdom, French from France, Portuguese from Portugal, Russian from Russia, Spanish from Spain) used in the most populous countries in Europe.