



[Press release]

New global survey to understand rare disease patients' experience of treatments

07 March 2019, Paris – [Rare Barometer Voices](#) today launches a new global survey to better understand rare disease patients' experience of treatments.

The online survey is available in 23 languages and open to participants from around the world.

Are you a rare disease patient, family member or carer?

Take action: [take part in the survey!](#)

Spread the word about the survey: share this link with your network: <http://bit.ly/eurordis-survey>

In 1999, the [European Regulation on orphan medicinal products](#) stated 'patients suffering from rare conditions should be entitled to the same quality of treatment as other patients'ⁱ. Yet, in a short survey conducted by Rare Barometer Voices in 2017, **24% of respondents said that they had not been able to get the medical treatment they needed in the last 12 months as it was not available in their country**, a figure which was 17% higher than for the general populationⁱⁱ. This new Rare Barometer Voices survey will provide a deeper insight into rare disease patients' experiences of treatments, which will be used to advocate for positive change for people living with a rare disease.

Sandra Courbier, Rare Barometer Programme Senior Manager, commented, "This survey will help us to better understand rare disease patients' experience of treatments and to generate facts and figures to help us to communicate these experiences to policy makers and institutions".

"Through asking questions such as whether treatments are available, whether these treatments are accessible and if these treatments have resulted in positive or negative experiences, we will be able to better measure and understand the unmet treatment needs of people living with rare diseases".

"The results will be analysed in a number of different ways to generate an overview of rare disease patients' experience of treatments at a global level as well as by country, disease group, gender and age".

"The results will be shared with patient organisations, policy makers and the general public and used in our advocacy work to drive real change for the rare disease community".

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Rare Barometer Voices

[Rare Barometer Voices](#) is the EURORDIS survey initiative that brings together over 8,000 rare disease patients, family members and carers who share their experiences and opinions on the issues that matter to the rare disease community.

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 of the programme 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 800 rare disease patient organisations from 70 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.

Rare diseases

The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. Over 6,000 different rare diseases have been identified to date affecting an estimated 30 million people in Europe and 300 million worldwide. Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offerings inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.

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ⁱ Regulation (EC) No 141/2000 of The European Parliament and of The Council of 16 December 1999 on orphan medicinal products. <https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2000:018:0001:0005:en:PDF>

ⁱⁱ Access to treatment : unequal care for European rare disease patients. A Rare Barometer survey. February 2017.
<http://download2.eurordis.org.s3.amazonaws.com/Access%20to%20treatment/access%20to%20treatment%20EN.pdf>