



[Press release]

New global survey to collect views of rare disease community on sharing of patients' health information

22 December 2017, Brussels – [Rare Barometer Voices](#) today launches a new survey to collect the experiences and views of rare disease patients, families and carers on how, with whom and for what purpose they want to share their health information.

The survey is available in 23 languages and open to participants 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: ow.ly/dqUH3ohlhyl

There are an increasing number of initiatives that involve the sharing of patients' health information, focusing, for example, on:

- Analysing symptoms reported by patients to better identify early signs of a disease.
- Analysing testimonies shared on social media to learn more about the effect of a treatment.
- Finding out how many people are affected by a disease to inform planning of national health services.
- Exploring why the number of people affected by a disease varies between countries.
- Helping people to manage their conditions by using smart phone apps.

Sandra Courbier, Surveys & Social Studies Manager at EURORDIS, commented, *"Through this new survey, we will be able to better understand how to share and protect patients' data. The concrete results we get from this survey will provide us with a real-life perspective on what it means for patients to share their health information, a perspective we will use to inform the policy makers behind data regulations, as well as the organisers of future initiatives so that they take into account patient preferences."*

She continued, *"We will be able to better understand how much control patients want to retain over their health information, as well as the risks and opportunities associated with the use of their genetic information. The results of the survey will form the basis of a new EURORDIS position paper on data protection."*

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Rare Barometer Voices

[Rare Barometer Voices](#) is the EURORDIS survey initiative that brings together over 7,000 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 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 eurordis.org.

Rare diseases

The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. Over 6000 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 offering 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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