



New H-CARE Survey to understand rare disease patients' experience of healthcare

13 December 2019, Paris – [Rare Barometer](#) today launches a new survey to better understand patients' experience of the healthcare they receive for their rare disease or complex condition.

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: tiny.cc/h-care

The H-CARE Survey is a non-profit initiative set up by four European Reference Networks (ERNs) related to kidney, lung and urogenital diseases and genetic tumour risk syndromes, with the support of Rare Barometer, the EURORDIS survey programme. The aim is to use this pilot survey to test the development of a common patient feedback mechanism across Europe, and across rare and complex diseases. The long-term goal is to scale up the survey to cover all 24 ERNs and to measure evolution of care over time.

Sandra Courbier, Rare Barometer Programme Senior Manager, commented, "This survey will help us to better understand rare disease patients' experience of the healthcare they receive and will help hospitals that are part of a European Reference Network to deliver better healthcare for people living with rare diseases or complex conditions".

"Through asking questions on topics such as whether patients receive a choice in their treatment, whether they receive emotional as well as physical care and their experience of follow-up care after a visit to a healthcare professional, we will be able to better measure and understand levels of satisfaction with the healthcare received".

"The results will also 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".

If you want to know more about the survey visit www.eurordis.org/about_hcaresurvey

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About European Reference Networks

[European Reference Networks](#) (ERNs) are virtual networks which bring together nearly 1,000 healthcare providers across Europe to tackle complex or rare medical conditions that require highly specialised treatment and a concentration of knowledge and resources. These networks ensure that medical expertise travels across borders so that patients don't have to. The four ERNs involved in this survey are [ERN GENTURIS](#), [ERN-LUNG](#), [ERKNet](#) and [eUROGEN](#).

About Rare Barometer, the EURORDIS survey programme

[Rare Barometer](#), the EURORDIS survey programme brings together over 10,000 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 survey software enables high-quality, secure data collection and analysis. The Programme was created to systematically collect patients' opinions on transversal topics and introduce them into the policy and decision-making process, transforming patients' and families' opinions and experiences into figures and facts that can be shared with a wider public and policymakers.

About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 800 rare disease patient organisations from over 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.

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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