EURORDIS survey results voice concerns over the subpar healthcare experience of people living with a rare disease

Survey shows that, on average, rare disease patients rate their healthcare experience 2.5 on a scale from one to five.[1]

3 February 2021, Paris – A new Rare Barometer survey report shows that **people with rare diseases give their healthcare experience a medium-low rating**. Based on over 3900 submissions received through the 2019-2020 H-CARE survey, the report outlines the major gaps in healthcare delivery and provides recommendations for future reform.

According to the respondents, healthcare services for rare and complex conditions only occasionally consider key aspects, such as follow-up consultations and appropriate psychological and social support. The H-Care survey findings indicate that there is still plenty of room for improvement and redesign of health and social services to meet the needs of people living with a rare or complex condition in Europe.

Moreover, the results show that **patients living with a rare disease have a worse healthcare experience than other patients affected by chronic diseases**. While both require multidisciplinary care and have broadly similar needs, patients with rare diseases seem to have a harder time accessing care that meets their needs.

Among the three **priority areas for improvement, the respondents indicated the need for follow-up consultations, more orientation on resources and support, and psychological assistance**. Timely follow-up is vital to ensure that the patient is aware of his or her diagnosis and moves forward with the prescribed treatment plan. Still to this day, many people living with a rare disease feel left alone with their concerns. Orienting patients towards community support groups, alongside adequate psychological and emotional help, emerges as a key factor in ensuring a better healthcare experience.

In order to support patients and carers, experts should also **improve coordination with other doctors** and provide recommendations to patients on how to manage the disease in their daily life, for instance by **setting specific goals or developing disease management programmes.**

"The results of this survey confirm that there is still work to be done to improve the healthcare experience of people living with a rare or complex condition. From providing appropriate psychological support and ensuring better care coordination to signposting to support groups. We invite healthcare providers, clinicians and hospital managers, and health and social care authorities to analyse the results, extract lessons, and use them to inform future service redesign and policy interventions", says Inés Hernando, ERN and Healthcare Director.

[1] H-CARE obtained the score for rare disease patients' healthcare experience by combining answers to 11 questions related to follow-up after consultations, information on treatments, care coordination, and managing patients' health in their daily lives.

Patients treated in ERN Centres of Excellence have a better healthcare experience

The survey was also used to assess the experience of health care received in Centres of Expertise belonging to four European Reference Networks (ERN LUNG, GENTURIS, ErkNet and eUROGEN). The results showed that patients treated in these centres had a better healthcare experience compared to those treated in other non-expert centres. Notwithstanding a higher score, areas for improvement for Centres of Expertise that belong to an ERN remain the same as for other non-expert centres.

Based on the survey responses, EURORDIS has outlined three recommendations to improve the healthcare experience of people living with a rare or complex condition:

1) **Going beyond diagnosis and medical treatment:** increase focus on follow-up after consultations, psychological support, and healthcare aspects that allow patients to manage their health in their daily life.
2) **Ensuring access to multidisciplinary and networked health care:** improve access to high-quality specialised care for people living with a rare or complex condition. This includes simplifying the national referral pathways to Centres of Expertise, facilitating timely access to in-person and virtual cross-border expert advice when such expertise is not available in their home country, and promoting knowledge sharing between Centres of Expertise and other healthcare providers.
3) **Developing and implementing a questionnaire to measure the healthcare experience of patients living with a rare disease and their caregivers:** contribute to setting quality standards for health care in rare and complex conditions. Such a questionnaire would need to include dimensions specific to these conditions and be flexible enough to adapt to the diversity of situations and profiles of the people living with rare diseases.

The survey report identifies these recommendations, backed with evidence-based examples from across the region, to inspire policy makers and healthcare stakeholders at EU, national and local level as they seek ways to improve the quality of care delivered to people living with a rare or complex condition in Europe.

Read the full report here.

Read the executive summary here.

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EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of 944 rare disease patient organisations from 73 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.

The Rare Barometer Programme

The Rare Barometer Programme is the EURORDIS survey initiative that brings together over 15,000 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 broader public and policymakers.

About 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. 72% of rare diseases are genetic whilst others are the result of infections (bacterial or viral), allergies and environmental causes, or are degenerative and proliferative. 70% of those rare genetic diseases start in childhood.

Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offerings inadequate, and research limited. Despite their significant overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment, and research benefits.

Contacts

For media enquiries, please contact**:**

Stanislav Ostapenko, Communications Manager, stanislav.ostapenko@eurordis.org, +33 1 56 53 52 61

Jessie Dubief
Research Executive ERN Pilots
EURORDIS-Rare Diseases Europe
jessie.dubief@eurordis.org
+33 6 81 35 81 41

Ines Hernando
ERN and Healthcare Director
EURORDIS-Rare Diseases Europe
ines.hernando@eurordis.org
+32 2 274 06 11