



3,000 rare disease patients & carers voice difficulties in balancing care & life

First Europe-wide survey on social impact of rare diseases publishes results

19 May 2017, Paris - The first Europe-wide [survey](#) on the social impact of rare diseases has revealed that rare diseases have a serious¹ impact on everyday life for **over 80% of patients and families**.

Over 3,000 rare disease voices across Europe responded to the survey '*Juggling care and daily life: The balancing act of the rare disease community*', which was conducted via [Rare Barometer Voices](#) and in the scope of the EU-funded [INNOVCare project](#), focused on promoting person-centred care for rare diseases.

Rare diseases are complex - they are characterised by a wide range of symptoms that vary from disease to disease and also between patients living with the same disease. The care needs of patients are therefore also complex. Patients need to simultaneously access different health and social services, and coordination of care is a challenge.

"The different professionals that I need to see are usually not coordinated and do not see the person as a whole, but just as parts of a body."
Female survey respondent, Spain

Dorica Dan, Member of the EURORDIS-Rare Diseases Europe Board and Chair of the Romanian Prader Willi Association, commented, "As a mother of a daughter living with a rare disease, I know only too well the burden that a rare disease can bring to everyday life. This survey confirms what we already knew to be true, that the time burden of care is enormous, as is the effect of a rare disease on social, work and school life. Rare diseases pose real challenges for the person affected as well as their family or those who assume caregiving responsibilities. Patients and families need person-centred care to connect the dots across the various health and social services."

The current context: European Pillar of Social Rights

The timely publication of these [survey results](#) comes after the European Commission's release of its first proposals for a European Pillar of Social Rights. [EURORDIS responded](#) to the European Commission's public consultation on the Pillar to highlight for the first time the specific issues surrounding rare diseases.

Raquel Castro, Social Policy Senior Manager at EURORDIS, commented, "The results of this survey clearly show the severe care and time burden on people living with a rare disease and their carers. These challenges are not always accounted for within the social care system. We need a European Pillar of Social Rights that promotes integrated health and social care as well as adapted employment to respond to the needs of people living with a rare disease and other complex chronic diseases."

Time burden & consequences on work life

The [survey results](#) show that the **time burden** of daily care management and care coordination for rare disease patients and families is substantial.

- **42%** spend **more than 2 hours** a day on care for their disease.
- **62% of carers** reported they spend more than 2 hours per day on tasks related to the disease while **nearly a third spend more than 6 hours a day on care for a patient** (in comparison,

¹ very severe, severe or medium

OECD figures² show that 50% of carers (for patients with any type of disease or dependent conditions) provide less than 1.4 hours of care a day).

- **At least 64%** of carers are women.
- **38%** of respondents declare that they were absent from work due to health-related problems for over **30 days in the last 12 months**.
- **41%** of patients and carers responded they need special leave at work but could not obtain it.

For the first time, the survey results provide robust data on the impact of rare diseases on everyday lives across Europe.

60% of the over 3,000 respondents that answered the survey are rare disease patients and the remainder family members of patients. The survey was conducted in 23 languages across 42 countries.

The survey covered issues surrounding the impact of rare diseases on daily life, including coordination of care, mental health, employment and economic impact. [See the full results.](#)

The survey is conducted in the scope of the [INNOVCare project](#), the first project in the area of rare diseases co-funded by the European Commission's Employment and Social Innovation (EaSI) Programme. The project brings together competent authorities, patient organisations, social services and academics including the Spanish Ministry of Health and Social Services, EURORDIS, the [NoRo Resource Centre](#) for Rare Diseases and the County of Salaj (Romania), as well as experts in social innovation and health economics, from the Centre for Social Innovation-ZSI (Austria) and from Karolinska Institute (Sweden).

EURORDIS thanks its members, other patient organisations, national rare disease alliances and patient representatives that helped to recruit participants for this survey.

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² OECD (2011), "The Impact of Caring on Family Carers", in *Help Wanted?: Providing and Paying for Long-Term Care*, OECD Publishing, Paris.

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Notes for editors

INNOVCare Project

The EU-funded [INNOVCare Project](#) gives a voice to the social and everyday needs of people living with a rare disease and addresses the need for person-centred care in European countries.

The project is developing and testing an innovative care pathway that links health and social services, using case management. A [pilot](#) is ongoing in Romania and its social and economic impact will be assessed by social innovation and health economics experts.



With the support of an [Advisory Group](#) composed of competent authorities from 15 countries, INNOVCare is also promoting discussions on how to implement similar care models across Europe in a sustainable manner. For more information visit www.innovcare.eu.

Rare Barometer Voices

[Rare Barometer Voices](#) is a tool to carry out EURORDIS quantitative surveys on issues affecting people living with a rare disease. It is made up of a community of over 5,000 people living with a rare disease who commit to regularly participate in surveys and studies. The Rare Barometer Voices survey software enables high-quality, secure data collection and analysis. Rare Barometer Voices covers 48 countries and all surveys are conducted in 23 languages.



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



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 over 60 million people in Europe and the USA alone. 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.