Press release

Rare disease patients support sharing of their health data while wanting to retain control of how and why data is used

15 July 2019, Paris - EURORDIS-Rare Diseases Europe today announces results from the first multi-country survey on rare disease data sharing and protection, published in the Orphanet Journal of Rare Diseases by EURORDIS and the School of Social Sciences of Cardiff University.

Over 2,000 rare disease patients, family members and carers from 66 countries representing 600+ diseases responded to the survey carried out from March – May 2018 through the Rare Barometer Programme.

The published article also includes a series of recommendations to inform and support policy makers, researchers, funders and patient organisations so they take into account patients' preferences when creating and implementing data-sharing initiatives.

The key findings of the survey show that:

- Close to **100%** of respondents (rare disease patients and patient representatives) are **supportive of data-sharing initiatives to foster research and improve healthcare**.[1]
- **9/10** people also support data sharing to improve research and care on **diseases other than theirs**. However, **over 40%** are also **against** their data being shared **outside the medical field**.
- **80% of respondents** want full or near to full control over the data they share. They want to decide **who** has access to their data, and **how** and **why** those people are using that data.
- Rare disease patients identified the **top two risks** associated with sharing data as their **information being shared with third parties without their consent** and it **being used in a context different from the one in which they disclosed it.**

The list of 7 recommendations includes, for example, that the governance of data-sharing initiatives should involve both **actors trusted by patients** (for example, GPs) and **involve patient organisations directly**, and that **funds** should be dedicated to informing patients on the progress and outcomes of the research.

> **Sandra Courbier, EURORDIS Survey Programme Senior Manager and co-author of the paper in which the results are published today**, commented, "Being in favour of sharing data and calling for more control are not contradictory; from these results we can see that patients have two parallel requirements. They are open to systems that allow them to both

[1] Comparison with general population: 37% would be ready to share data to develop medicines and treatments

> share their data and equally retain control over who can access this data and how they will use it."
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> **Virginie Bros-Facer, EURORDIS Scientific Director and co-author of the paper, added,** "Sharing data is imperative in the context of research. Rare disease patients know this more than anyone. Data sharing enables a much deeper and broader understanding of the nature of disease and patient populations than was previously possible. It can provide a greater evidence base for improving clinical outcomes, supporting the development of drugs and devices. It speeds up the diagnostic process, improve its accuracy and consequently reduce health costs."

The recommendations are developed based on an extensive consultation (made up of the multi-country survey, previous qualitative studies and patient discussion groups), across European projects including RD-Connect, and in cooperation with the School of Social Sciences at Cardiff University.

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About 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.

About the Rare Barometer Programme

The Rare Barometer Programme is the EURORDIS survey initiative that 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.

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