



Media Statement

EURORDIS responds to European Parliament adoption of legislation on health data space

24 April 2024, Brussels – EURORDIS – Rare Diseases Europe has welcomed the newly adopted position of the European Parliament on the European Health Data Space (EHDS) proposal. A total of 445 Members of the European Parliament voted in favour of the regulatory framework.

The EHDS is a proposed EU regulatory framework aimed at facilitating the access, sharing, and use of health data across EU Member States to improve healthcare delivery, research, and policymaking.

Responding to the results of the European Parliament's vote on the EHDS regulatory framework, **Jelena Malinina**, Data Director at EURORDIS, said:

"The European Parliament's support for the EHDS marks a significant legislative advance toward modernising and optimising data usage and sharing practices across the EU.

"We are greatly encouraged by the Parliament's adoption of measures that would ensure patients' immediate access to health data. These measures would empower patients by providing them with direct access to their personal health data processed within health services, including indispensable information like patient summaries and laboratory results. Such transparency and immediacy in accessing one's own health information is critical, especially for the rare disease community where timely information can significantly influence treatment outcomes.

"The establishment of facilitated data management services by Member States will majorly improve how individuals interact with their health data across borders. This will enable patients to not only access but also manage proxy authorisations, correct inaccuracies, and control who accesses their information, thus enhancing personal data sovereignty.

"The introduction of a unified access protocol and the reinforcement of data protection measures are also pivotal, as they ensure that health data is used responsibly and ethically by researchers and institutions.

"Moreover, the agreement reached on intellectual property ensures that data containing intellectual property or trade secrets can be used for secondary purposes while implementing safeguards to prevent data holders from denying access requests. This approach carefully balances privacy concerns with the necessity for data accessibility.

“The option for users to opt out of secondary data usage without needing to provide a reason is crucial for preserving trust and autonomy within the health data ecosystem, so we value the inclusion of this.

“While we appreciate the Parliament’s adoption of the EHDS regulation, we urge national governments and EU institutions to invest in digital and health literacy, enabling patients, caregivers, and professionals to effectively use these new tools and advocate for their healthcare needs.

“We urge EU policymakers to collaborate closely with the rare disease community in the upcoming legislative term to effectively implement the European Health Data Space (EHDS) proposals. This initiative is crucial to meet the specific needs of our community and to develop a comprehensive, equitable health data ecosystem that enhances the quality of life for the 30 million Europeans living with a rare disease and their families. It is also essential to bolster the EHDS infrastructure to ensure robust and secure systems that facilitate seamless, secure data access across borders.”

About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 1,000 rare disease organisations from 74 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting people, families, and rare disease 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 services.

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