



Media statement

EURORDIS welcomes European Parliament vote on European Health Data Space

13 December, Brussels – EURORDIS-Rare Diseases Europe has today welcomed the European Parliament’s plenary vote on the European Health Data Space (EHDS), which acknowledges the progress made on building a common regulatory framework for the improved use of health data, while also calling for further enhancements to the proposed legislation.

By 516 votes to 95, Members of the European Parliament (MEPs) voted to adopt the joint report from the European Parliament's Committee on Environment, Public Health and Food Safety (ENVI) and Committee on Civil Liberties, Justice and Home Affairs (LIBE).

Responding to the vote, **Jelena Malinina**, Data Director at EURORDIS, said:

“Data is vital to progress knowledge on rare diseases and to address this important public health concern. The EHDS can offer new opportunities to ultimately improve the lives of people with rare diseases through enhanced and safe access to data as well as through advancing diagnosis, treatment, care and research for rare disease patients.

“Patients with rare diseases strongly support data sharing to enhance healthcare and research, as long as their rights are upheld. It’s crucial that their preferences regarding data sharing, privacy, security risks, and the ethical aspects of big data usage are considered.

“The European Parliament’s affirmed position on the EHDS is commendable, particularly for its provisions on enhancing patient access to personal health data and improving data quality and security. As negotiations between the Parliament, Council and Commission approach, we urge EU policymakers to prioritise instituting mechanisms that facilitate data sharing, while guaranteeing robust data protection and privacy.

“The EHDS should also be aligned with key pieces of EU legislation, including the GDPR. It is also imperative to establish clear consent protocols for secondary data use, incorporating advanced anonymisation and pseudonymisation techniques. Strong oversight and additional security measures are equally essential.

“Furthermore, the inclusion of a wide range of civil society representatives, including from the rare disease community, in the governance of the EHDS is crucial.

“Ultimately, it’s essential to acknowledge the extensive logistical and technical challenges inherent in developing and implementing the EHDS. This endeavour demands significant resource commitments, dedicated time, and concerted political efforts. This is a project that must not be undertaken in a hasty or fragmentary manner.

“Nonetheless, the modernisation of data systems is crucial for European health services and the 30 million individuals living with rare diseases across Europe. These updated systems must fully leverage modern technology to ensure that no patient is left behind.”

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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