



Media statement

EURORDIS welcomes provisional agreement on the European Health Data Space

15 March 2024, Brussels – The Council of the EU and the European Parliament have reached a provisional agreement on the regulation to establish the European Health Data Space (EHDS).

The EHDS is aimed at facilitating the sharing and access of health data across EU Member States to improve healthcare outcomes, research, and policymaking, while safeguarding data security and privacy.

Responding to the provisional agreement, **Jelena Malinina**, Data Director at EURORDIS-Rare Diseases Europe, said:

“This agreement represents a major legislative step forward, which will offer a lot of renewed hope to the 30 million people in Europe facing rare diseases. For our community, the sharing of health data is crucial, as the challenges of rare disease healthcare and research are often magnified by the geographical dispersal and limited availability of data. 95% of Europeans impacted by rare diseases are eager to contribute their data for the greater good, and so we hope that this agreement will harness our community’s willingness to propel scientific research and improve clinical practices in tangible, life-altering ways.

“We commend and support the policymakers’ pledge to implement the European Health Data System promptly and before the rapidly approaching end of the EU’s legislative term.

“We also welcome the provision for EU citizens living with a rare disease to access their prescriptions, imaging, and lab tests electronically, regardless of their location within the EU. This represents a significant leap towards dismantling barriers to care.”

“Balancing the scales between patient data privacy and the necessity of data sharing for research had been a pivotal aspect of the negotiations. The initial proposals ranged from the European Commission’s restrictive approach to patient rights, to the European Parliament’s advocacy for broader opt-out options, and finally, to the Council’s call for a more nuanced method. EURORDIS is dedicated to thoroughly examining the legal text to ensure that the compromise reached genuinely benefits those with rare diseases.

“As we await the final text’s adoption in April 2024, we will thoroughly examine its legal details to fully assess how, and the extent to which, it will benefit our community. This agreement is only the start of a journey towards a future where every data point can open up new possibilities for improving the lives of those living with rare diseases.”

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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