

## A Step Closer to the European Health Data Space

The proposal for a regulation on the European Health Data Space (EHDS) presents a unique opportunity for countries in the European Union to harness the power of health data to improve healthcare outcomes and reduce health disparities. However, whether the EHDS will be successful in that depends on a number of factors, including but not limited to the digital health literacy of EU citizens and healthcare providers, and the readiness of EU member states in terms of infrastructure and technological capabilities, as well as implementation deadlines. Given that the members of the European Parliament (MEPs) have tabled over 2,100 amendments to the Commission's original text, it is very likely that the final version of the EHDS regulation will differ considerably from the initial proposal.

One area of contention between the Commission and the European Parliament seems to be around the secondary use of health data. Under the original proposal, anonymized and pseudonymized health data could be accessed by third parties (under specific rules and conditions) to support research, innovation, and public health policymaking without the citizens' consent. The majority of MEPs, on the other hand, argue that these public health benefits need to be balanced against the citizens' privacy rights. Despite agreeing on a need for a consent-based model for the secondary use of health data, the Parliament is divided on whether this consent should be explicitly sought from citizens (opt-in model) or assumed with the possibility of citizens revoking that consent (opt-out model).

Furthermore, both the Commission and the European Parliament will also need to take into consideration the interests of the Council and the member states that it represents (which have already signaled that telemedicine should be completely scrapped from the scope of the regulation). With the interinstitutional dialogues underway, more compromises on the EHDS proposal are expected.

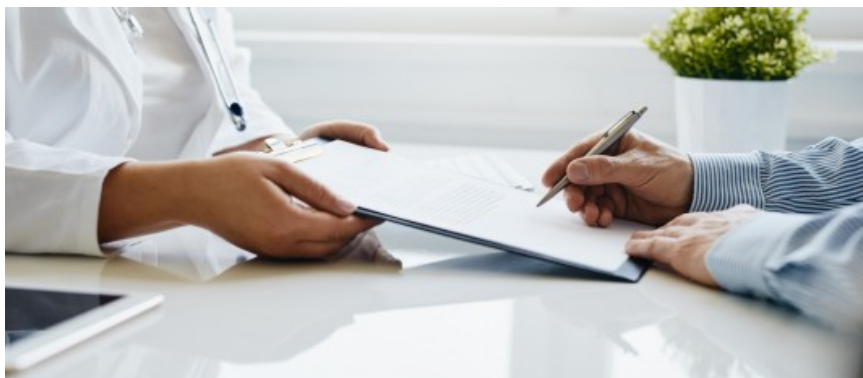
For EPHA, improving citizens' digital health literacy, incorporating a wider range of civil society stakeholders in the EHDS governance model, having provisions on public return on investment, and realistic implementation deadlines remain key recommendations for an EHDS that truly empowers citizens and serves their best interests.



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*Guest article by the European Respiratory Society*

In a fast-paced ever-changing world, research and the free flow of scientific data are key to ensure Europe's healthy population as well as to prepare for new health challenges. A well-functioning European Health Data Space (EHDS) is a key step in the right direction to ensure that the European Union (EU) remains at the forefront of medical research. Simply put, data saves lives.

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*Guest article by the European Association of Hospital Pharmacists (EAHP)*

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*Guest article by the European Organisation for Rare Diseases (EURORDIS)*

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## **Furthering the use of health equity data: Roma in segregated clusters in Hungary**

*Guest article by Feras Kesabji and János Sándor, University of Debrecen*

While Europe is furthering its work on the European Health Data Space, it is important to keep in mind the needs of people in vulnerable situations. Health equity data can help clear up many unclaritys when designing social inclusion policy on the national level. Take the example of Hungary's Roma people; the health status of Roma in Hungary is well behind the national average, which is backed up by research. However, the extent of the problem is difficult to fully understand because of a lack of Roma-specific indicators in routine health monitoring.

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