TGEU publishes explainer: What the European Health Data Space means for trans people

publication, health and depathologisation

This is a brief resource introducing the European Health Data Space (EHDS) adopted by the European Union in 2025. This resource tries to answer some basic questions about the EHDS and identifies the advantages and risks of processing trans people's electronic health data in a shared network.

What is the European Health Data Space?

The Regulation on the European Health Data Space (EHDS) is a new governance framework to regulate the integration of the health data spaces of different EU Member States. A health data space is a secure, common infrastructure of rules, standards, and governance for sharing electronic health data. It aims to strengthen the region's healthcare systems by **improving access to electronic health data** both inside individual EU Member States and across the region for various purposes, such as

- the provision of healthcare
- research
- policymaking and regulation.

The EHDS sits within a broader set of patient-centred health initiatives at the EUlevel, including e-prescriptions, electronic patient records, and **access to cross-border healthcare within the EU**.

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Future outlook

There are still many unknowns about how the EHDS will be implemented. By March 2027, the European Commission is expected to set various standards for the collection and registration of personal electronic health data as well as the anonymisation of electronic health data. Due to the sensitive nature of the health data involved, it is important to take note of these developments and track them, and check with your healthcare providers when and how they process your health data.

Further, the extended period of implementation of the EHDS at the national level offers opportunities to trans organisations for engagement. The involvement of trans communities in the implementation of the EHDS at the national level and in addressing privacy and data protection risks specific to trans people will help address many of the concerns outlined in this paper. Trans health activists and organisations must work closely with patient advocacy organisations at the national level to ensure that concerns around trans people's experiences of barriers to healthcare access, especially in the digital sphere, are adequately reflected in civil society engagement with national governments.

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If you would like to learn more about the EHDS or connect with patient advocacy organisations at the national level, please reach out to our Policy team (policy@tgeu.org).

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