

European Health Data Space needs to protect patients and workers' rights



(5 April 2022) As the European Commission prepares to unveil its proposal on a European Health Data Space, EPSU underlines the need for a purpose-driven framework that improves quality-of-care outcomes.

As the voice of health and care workers in Europe, EPSU strongly believes that a human rights approach is essential to this framework. We cannot trust nor rely on an approach that would give commercial interests (from companies seeking profits) any role in a health data sharing space. Health is not a commodity and commercial interests can have no place in our public and private health issues.

According to the Commission, the proposal will:

- promote safe exchange of patients' data and citizens' control over their health data

- support research on treatments, medicines, medical devices and outcomes
- encourage the access to and use of health data for research, policy-making and regulation, with a trusted governance framework and upholding data-protection rules
- support digital health services
- clarify the safety and liability of artificial intelligence in health.

EPSU stresses the importance that the framework protects patients' rights to control their data. An ill-conceived European Health Data Space could lead to breaches of data confidentiality, dehumanization of health, unequal access to care due to limited digital literacy and [increased profit making](#) by private companies on shared data. These negative outcomes must be considered and addressed in the proposal.

Furthermore, the proposal must ensure that the use of AI will not lead to greater discrimination and unequal treatment between patients. Health workers, as well as patients, should be provided with adequate training to improve their knowledge about health data and AI to ensure that they are confident in using them.

Finally, the European Health Data Space must be developed with full transparency and in line with the existing regulations on data protection. Given that health is a public good, and equal access to it is one of the fundamental rights, it is crucial to serve this principle and to contribute to improving quality of care. There must be strong public sector involvement to ensure that health data are treated as public good and are not commodified for profit.

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