

Българска Асоциация
за Застъпване на Пациентите



Austrian Federal
Chamber of Labour
Brussels Office



Berufsverband Deutscher
Psychologinnen
und Psychologen



EDRi20
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Innovationsverbund
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Joint Public Letter to EU lawmakers on patients' rights in the European Health Data Space

Brussels, 13 April 2023

To European lawmakers:

We, the undersigned organisations representing **patients, medical professionals, persons with disabilities, consumer and digital rights organisations, as well as workers and trade unions**, urge you to uphold European patients' fundamental rights when pursuing the digitisation of our health systems and add an 'opt-in' consent requirement for the secondary use of health data to the proposed European Health Data Space (EHDS).

While we welcome the EHDS's aim to create interoperable and modern digital health systems across the EU, the European Commission's proposal unfortunately fails to protect patients when it comes to the sharing and use of their personal medical information by third parties.

The EHDS proposal claims to give individuals more control over their private information, but in fact it does the exact opposite: it completely deprives them of that control. Under the rules proposed by the Commission, **patients would have no say over the sharing and commercial exploitation of their data** and would not even be informed about who receives it.

"Respecting the confidentiality of health data is a vital principle in the legal systems of all the Contracting Parties to the [European] Convention [of Human Rights]. It is crucial not only to respect the sense of privacy of a patient but also to preserve his or her confidence in the medical profession and in the health services in general."

(European Court of Human Rights)

As a result, the proposal overrides the long-established principle of doctor-patient confidentiality and blatantly undermines the most fundamental principles of privacy established

by GDPR, namely that the collection and processing of health data requires the data subject's consent, except for narrowly defined circumstances.

Instead of acknowledging and safeguarding the special protections afforded to our medical records by GDPR and the European Courts' highest jurisprudence, **the EHDS proposes to legally compel physicians and hospitals to betray that confidentiality** and share sensitive medical information with state-run data processing facilities. Those facilities would in turn make that data available to third parties, including for commercial use.

The undersigned organisations therefore urge European lawmakers to **amend the EHDS proposal such that it requires data users to obtain valid consent from patients whose personal medical records they would like to use for secondary purposes.**

An 'opt-out' regime as proposed by the Rapporteurs' draft report in the European Parliament is not an adequate alternative because it unduly puts the burden of knowledge, understanding and decision on patients at a time when they are in most vulnerable situations of dealing with illness and other health problems.

If the European Health Data Space truly is about giving people control over their medical data and building trust in Europe's new digital health infrastructure, it must earn this trust.

SIGNATORIES

Association for Patients Defence, Bulgaria

AK EUROPA (Federal Chamber of Labour Brussels Office), Austria

Berufsverband Deutscher Psychologinnen und Psychologen e.V. (Organisation of German Psychologists), Germany

Bündnis für Datenschutz und Schweigepflicht (Alliance for Data Protection & Medical Confidentiality), Germany

Deutsches Psychotherapeuten Netzwerk (Network of Psychotherapists), Germany

European Digital Rights, EU

European Disability Forum, EU

European Federation of National Organisations Working with the Homeless, EU

European Public Services Union, EU

European Sex Workers' Rights Alliance, EU

Freie Ärzteschaft e.V. (Association of Independent Doctors), Germany

Health Action International, Netherlands

Innovationsverbund Öffentliche Gesundheit (Public Health Innovation Alliance), Germany

Patientenrechte und Datenschutz e.V. (Association for Patient Rights & Data Protection), Germany