

Betreff: EHDS vote on 24 April – compromise endangers medical secrecy

Von: "Jan Penfrat (EDRI)" <jan.penfrat@edri.org>

Datum: 16.04.2024, 10:06

An: BREYER Patrick <patrick.breyer@europarl.europa.eu>

Dear Patrick Breyer,

Next Wednesday, 24 April, you will vote in plenary on the [compromise deal](#) that ENVI rapporteurs and the Presidency reached for a new European Health Data Space (EHDS).

Unfortunately, this deal represents a real-world danger to the oath of medical secrecy by which doctors and other medical professionals are bound in Europe.

The undersigned organisations therefore call on you to reject the EHDS deal and demand the new Commission goes back to the drawing board.

In its current form, the EHDS deal will **expose everybody's medical records to unnecessary security and privacy risks** in the name of research and "innovation". It legally mandates every hospital and doctor to share the private medical data from every single patient—for the purpose of secondary use, i.e. unrelated to the patient's treatment—through a national agency, the so-called health data access body. Exactly how and what patient data is going to be shared may vary from member state to member state.

To make matters worse, the EHDS deal introduces a **misleading "opt-out"** from secondary data use that looks to patients as if they could object to it; but in reality will still allow member states to override it on vague arguments of "public interest" and "public tasks". For this to work in practice, member states need to collect all the data in the first place, which in itself creates [massive cybersecurity risks](#) in times at which data breaches, accidental or due to foreign adversaries breaking in, are happening regularly.

The EHDS deal **does not limit who gets access** to everyone's health data for secondary use and allows broad access purposes. Any "natural or legal person" can request an access permit, according to the compromise, as long as their research contributes to "public health or health technology assessment" or ensures "high levels of quality" of health care and related products and services. That expressly includes the training and testing of algorithms, AI systems, and digital health apps, and opens the door to **data abuse by tech companies** from all over the planet.

At the same time, the deal **fails to require companies to charge fair prices** and ensure widespread accessibility of the products and services that were developed using EU citizens' health data, so that EU citizens and health systems actually benefit from the data they provide.

This EHDS deal puts more emphasis on the profits of large pharma and big tech companies than it does on patients' rights.

As organisations representing patients, medical professionals, persons with disabilities, medical workers, and digital rights we have no choice but to call on you to reject the EHDS compromise and put the new Commission back to the drawing board.

Europe's digital health systems need to be more trustworthy than this. Now it is up to you to ensure they are.

Thank you for your support!

The undersigned:

[European Digital Rights \(EDRi\)](#), EU

[European Disability Forum](#), EU

[Freie Ärzteschaft e.V.](#), Germany

[Health Action International](#), Netherlands

[Innovationsverbund Öffentliche Gesundheit e.V. \(InÖG\)](#), Germany

[medConfidential](#), UK

[Patientenrechte und Datenschutz e.V.](#), Germany

[SOMO, the Centre for Research on Multinationals](#), Netherlands

--

JAN PENFRAT (he/him)

Senior Policy Advisor

Mobile/Signal: +32 470 839 044

Matrix: @jan:penfrat.net

EUROPEAN DIGITAL RIGHTS

www.edri.org | [Mastodon](#) | [PGP](#)

Working days are Monday-Thursday