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Investigating users' attitudes on electronic health data sharing

Report

A new report commissioned by Greens/EFA takes a closer look at the European Health Data Space and analyses users' attitudes on sharing electronic health data as part of the proposed EHDS Regulation. The findings need to be taken into account by the co-legislators working on the EHDS Regulation.

- **READ THE FULL REPORT (PDF)**
- **FULL DATA 1**
- **FULL DATA 2**
- **METHODOLOGY BY IPSOS**

Background:

The Commission proposal for a Regulation on the European Health Data Space (EHDS) is part of the Commission's European strategy for data. The proposal aims to facilitate sharing of electronic health data across different players of the European data economy by achieving three main objectives.

First, it aims to increasing data subjects' rights to data portability and interoperability to strengthen their control and access to data in cross-border situations for the provisions of care.

Second, it tries to introduces horizontal and harmonized rules for economic operators that introduce digital health products, such as electronic health record (EHR) systems, including electronic health records (EHR);

Third, it lays down a framework for secondary access and use of electronic health data by private and public bodies to, inter alia, develop new products, innovative practices, conduct research, and regulatory practices in the field of public and occupational health.

The aim of this report is to provide an overview of EU citizens' attitudes to primary and secondary use of electronic health data as proposed by the EHDS proposal, by taking account of country-level, gender-level, age-level, and education-level differences.

Overall, it emerges citizens' demands for greater user-level control before making available their electronic

health data via the EHDS. In particular, the findings highlight that

1. Respondents overwhelmingly prefer to make their electronic patient records accessible to third parties based on explicit consent;
2. Respondents prefer to grant access to their electronic health records to scientists and researchers;
3. A strong majority of respondents wish to express consent before giving access to scientists and researchers;
4. Most respondents prefer to share their personal data only for general or specific health-related purposes and not for commercial ones;
5. Respondents feel more protected when health public health authorities protect their data, contrary to government private actors;
6. Respondents claim to understand “well” the risks and benefits associated with sharing data via their electronic health records.

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Responsible MEPs



Patrick Breyer

Member



Tilly Metz

Member

Contact person



Nikolaus Riss

Press & Media Advisor DE (German language press)

Attached documents

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Full data_EHDS survey
Full data 2_EHDS survey
Methodology EHDS Report by Ipsos

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