

Wednesday, April 5th, 2023 2: Press releases Use of health data requires trust - urgently improve the draft for the European Health Data Space! press release

the conference of the independent data protection supervisory authorities of the federal and state governments

The conference of the data protection supervisory authorities of the federal and state governments (data protection conference) calls for improvements to the draft regulation for the European health data space so that the data protection level of the General Data Protection Regulation and Articles 7 and 8 of the Charter of Fundamental Rights of the European Union is not undermined. In its now published statement of March 27, 2023, the data protection conference criticizes the European Commission's draft regulation on the creation and regulation of a European Health Data Space (EHDS). The data protection conference thus complements the criticism of the European Data Protection Board. The European health data space is intended to enable and standardize the use of electronic health data for treatment purposes (primary use) throughout Europe. To this end, it should be possible to mutually access information in the systems of the Member States. The draft ordinance also provides for regulations on various secondary uses, including training artificial intelligence, for research purposes or purely for educational purposes. Above all, the Data Protection Conference criticizes that the present draft regulation does not yet adequately balance the fundamental right to data protection and the right to informational self-determination with the various interests of use. In particular, she calls for improvements in relation to the rights of those affected, legal clarity and regulations on technical and organizational measures. Patients have the right to secure and confidential processing of their health data. Data subjects must be able to control their electronic health data in the European Health Data Space. The data protection conference criticizes the fact that it is not clear whether, and if so, to what extent, the persons concerned are granted any rights at all, particularly in the case of the planned secondary use of electronic health data. The data protection conference also calls for the envisaged regulation on the provision of personal genome data to be deleted, as this encroaches on the most intimate area of the persons concerned and their relatives. From the point of view of the data protection conference, the technical implementation to ensure a high level of security must also be better regulated. H. c. Marit Hansen, chairwoman of the data protection conference in 2023, emphasizes the importance of a trustworthy and legally clear regulation as the legal foundation for the European health data space: "This is about health data, which is particularly sensitive and has a high need for protection. Misuse or data breaches can have drastic consequences for the persons concerned." The data protection conference calls for suitable guarantees through the use of methods in the sense of data protection "by design" and

“by default” – also with methods of anonymization, pseudonymization or encryption. The more sensitive personal data is, the stricter the requirements for processing it must be. For the necessary transparency, precise and easily understandable information about the processing must be provided. Hansen makes it clear: “The entire health data room system must be trustworthy. This can only be achieved if the data protection standards resulting from the General Data Protection Regulation and the European Charter of Fundamental Rights are not undermined

[://datenschutzkonferenz-online.de/media/st/2023-03-27\\_DSK-Stellungnahme\\_EHDS.pdf](https://datenschutzkonferenz-online.de/media/st/2023-03-27_DSK-Stellungnahme_EHDS.pdf) [Extern]

The opinion of the European Data Protection Board "EDPB-EDPS Joint Opinion 03/2022 on the Proposal for a Regulation on the European Health Data Space" is available at: <https://edpb.europa.eu/our-work-tools/our-documents>

[/edpb-edps-joint-opinion/edpb-edps-joint-opinion-032022-proposal\\_en](#) [External]

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