Press release of the conference of the independent data protection supervisory authorities of the federal and state governments of November 24, 2022

DSK resolves demands for research with health data

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At its 104th conference, the conference of the independent data protection supervisory authorities of the federal and state governments (DSK) provides orientation for the scientific processing of health data. The chairman of the DSK, the Federal Commissioner for Data Protection and Freedom of Information (BfDI), Professor Ulrich Kelber, said: "Scientific research brings necessary and decisive advantages to our society. It is important to enable research while protecting the fundamental rights of citizens. Because they are the focus of this research and must not be made a mere object of data processing. We will only be able to do this with transparent and comprehensible rules. With the best legal and technical protection for the data subjects. With advice and monitoring by the data protection supervisory authorities. And through a legal regulation of research secrecy. The DSK has been demanding the last point in particular since 2004. Our resolution shows that data protection and research with health data are possible at the same time."

For the DSK, the basic guarantees and measures also include the topics of encryption and pseudonymisation of the data by a trustee, as well as the earliest possible anonymisation. Because when using anonymous data sets, researchers can use this data extensively. A central register directory and a central coordinating office with a pilot function are also among the demands of the DSK. Overall, the principle should apply that data can be used more extensively and specifically, the higher the protection of the data subjects through suitable guarantees and measures.

The newly founded TaskForce Research Data chaired by the BfDI and the Hessian Commissioner for Data Protection and Freedom of Information played a key role in the creation of the resolution.

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Contact:
The Federal Commissioner for Data Protection and Freedom of Information Graurheindorfer Straße 15353117 Bonn Email:
pressestelle@bfdi.bund.de

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