

Conference Session: The EU GDPR and a Code of Conduct in the Area of Health

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Abstract

The EU General Data Protection Regulation (GDPR) is not easily accessible to non-lawyers. Furthermore there is room for interpretation with regards to areas that are relevant for research. By developing codes of conduct under Art. 40 of the GDPR, guidance can be provided to researchers and administrative staff. If successful, the Code could provide clarity in the field of health research and function as a model to Member States with regards to the interpretation of the GDPR in the context of research.

The development of the Code will take a strong participatory approach and include Research Infrastructures, patient advocacy groups and industry representatives in the drafting process. The Code is directed at data controllers who process personal data for purposes of scientific research in the area of health, namely researchers and research institutions, biobanks, health databases and registries. The aim is to contribute to the proper application of the GDPR, taking into account the specific features of processing personal data in the area of health, as well as to clarify and specify certain rules of the GDPR. Furthermore the Code aims to assist in fostering transparency and trust in the use of personal data in the area of health research.
